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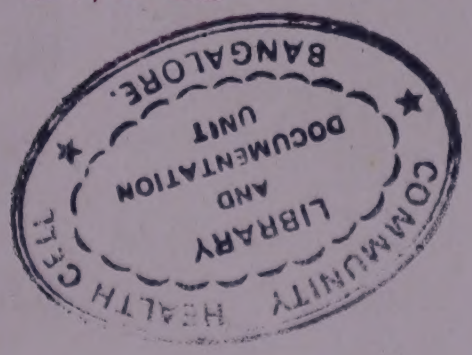

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y de Salud Internacional

Report on the

XI. International Conference on AIDS

Vancouver, Canada

July 7th to 12th, 1996

by Joachim Rüppel

October 1996

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Present Situation and Recent Trends of the Pandemic

Global overview

The *François-Xavier Bagnoud Center for Health and Human Rights of the Harvard School of Public Health* and *Joint United Nation Programme on HIV/AIDS (UNAIDS)* made up to now competing estimates of the magnitude and the epidemiological tendencies of the pandemic causing confusion and even doubts about the real figures. Both institutions together with the *AIDS Control and Prevention Project of Family Health International* co-organized a Satellite Symposium to review the current status and trends aiming at the elaboration of more accurate and consistent estimates. The results and conclusions were presented in a provisional report.

According to this document a cumulative number of 27.9 million HIV infections, 25.5 million among adults and 2.4 million in children, have occurred world-wide since the beginning of the pandemic until mid-1996. The majority of the infections - 26 million (93%) - were registered in the developing world.

In mid-July 1996 an estimated 21.8 million people, 21 million adults and 800,000 children, were living with HIV/AIDS. Of these, 20.4 million (94%) have their domicile in a developing country. The regional distribution is presented in the following table.

Estimated Number of Persons Living with HIV/AIDS - July 1996

Region	Number	Percent
Sub-Saharan Africa	14 million	64.2
South and South-East Asia	4.8 million	22.0
Latin America and the Caribbean	1.6 million	7.3
East Asia and the Pacific	35,000	0.1
North Africa and the Middle East	200,000	0.9
Eastern Europe and Central Asia	30,000	0,1
North America	780,000	3.5
Australia and Pacific	48,000	0.2
Western Europe	470,000	2.1
Global Total	21.8 million	100.0

During 1995, 2.7 million HIV infections occurred among adults world-wide averaging 7,400 new infections per day. Of these, 1.4 million infections were in sub-Saharan Africa and about 1 million in South and Southeast Asia. The industrialized world accounted for about 55,000 new infections in 1995 (2% of the global total).

In the same year 500,000 infants were born with HIV infection (about 1,400 per day); 67% of these children were in sub-Saharan Africa, 30% in South and Southeast Asia and 2 to 3% in Latin America and the Caribbean.

Of the adults living with HIV/AIDS, 12.2 million (58%) were male and 8.8 million (42%) were female. Currently, close to half of the 7,500 people who become infected daily are women.

More than 6 million adults have developed AIDS from the beginning of the pandemic to July 1996, and of these 4.5 million were in sub-Saharan Africa, 400,000 were in Latin America and 750,000 were in North America, Europe and North and South Pacific combined. In South and Southeast Asia where the pandemic gained intensity more recently, it is estimated that 330,000 adults have developed AIDS. Of the 1.6 million children with AIDS, 1.4 million (85%) were in sub-Saharan Africa.

The figures above presented evince that resource constrained countries and socially marginalized populations bear a disproportionate and progressively increasing burden of the pandemic.

Africa and the Middle East

By mid-1996, 13.3 million adults (more than 5% of all adults aged 15-49 in this part of the world) were living with HIV/AIDS in sub-Saharan Africa. In several countries of eastern and southern Africa (viz. Kenya, Malawi, Rwanda, Tanzania, Uganda, Zambia, Zimbabwe) where HIV began to spread widely in the early 1980s, more than 10% of women attending antenatal clinics surveyed in urban areas have been found to be HIV-infected, with rates which may exceed 40% in some surveillance sites. In these populations, transmission of HIV occurs mainly through heterosexual contact, beginning in early teen years and peaking before the age 25. In other sub-Saharan countries - mostly in west and central Africa - HIV epidemics are currently passing through their intermediate stage where between 1 and 10% of women attending antenatal clinics are infected with HIV.

HIV-2 is primarily found in West Africa and, in contrast to the increasing spread of HIV-1, the prevalence has remained rather stable in this region. This is thought to be the result of the higher transmissibility of HIV-1 compared to HIV-2.

Epidemics may suddenly explode with rates of infection increasing several fold within only a few years, as has been observed recently in Botswana and South Africa. Population mobility, patterns of sexual behavior and other related societal factors are likely to enhance the potential for such explosions but are not yet fully understood.

Besides their direct consequences for the health of adults, especially women, and infants the role of STDs in facilitating the transmission of HIV has been clearly established. The World Health Organization estimates that 65 million new cases of curable STDs occurred during 1995 in this continent.

Heterosexual contact represents the principal mode of transmission of HIV in adults and young people in sub-Saharan Africa. HIV antibody testing of blood donations remains incomplete in most countries of this region. Transfusions of unscreened blood account for less than 10% of infections, but play a role in the spread of HIV mainly to women of reproductive age and children.

Urban and trading centers generally continue to have substantially higher prevalence of HIV than rural areas. But as a result of population displacement, armed conflicts, proximity to highways, intense migration, lack of basic services and other structural conditions, some rural communities of Kenya, Tanzania and Uganda suffer higher infection rates than those observed in neighbouring urban populations.

Epidemics tend to spread into younger populations, especially young women. The rates of newly acquired HIV infections are highest in the 15-24 year old group among both females and males in most countries of the region. The peak of new infections occurs several years earlier in young women than in young men. Apart from biological factors, early sexual initiation and the patterns of sexual mixing, wherein young women tend to have sex with older men in the context of marriage or in exchange for money or benefits represent important reasons for the disproportionate risk of young women to acquiring HIV infection. For many women the major risk factor for HIV is the sexual behavior of their spouse or regular partner.

The constantly growing burden of disease has already overwhelmed the coping capacity of urban health systems in hard hit countries. In future, demands for care will increasingly fall on poorly equipped and under-funded rural services, households and individuals.

Demographic surveys in several countries have already noted significant increases in infant and child mortality. Studies in areas where 8% of the adult population is HIV-infected have measured a doubling of mortality due to HIV and a decrease of 5 years in life expectancy. Due to high levels of fertility, populations will generally continue to grow but critical deficits will affect the economically active ages.

The region of North Africa and the Middle East represents 22 countries ranging from Morocco in the West to Pakistan in the East. Information is sparse, but available data from screening of blood donors indicates low HIV prevalence in these populations, except for Djibouti. Recently, increases of infection rates in STD patients have been observed in countries like Sudan, Yemen, Pakistan and the Syrian Arab Republic. The region is characterized by late introduction of the virus, the marginal status of women in society, the highly stigmatising nature of STDs and the difficulty of conducting effective sexual health programmes.

To date in sub-Saharan Africa, there has been a general lack of rigorous evaluation of intervention strategies, especially those designed to reduce the sexual transmission of HIV. But in a recent study in Mwanza, Tanzania, early treatment of STDs in rural communities has been associated with a 42% decline in the rate of newly acquired HIV infections as compared to populations which served as controls.

Hope that the number of new infections may have decreased comes from studies in Uganda. Between 1990-93 and 1994-95, prevalence in pregnant women at 6 sentinel sites declined 29% overall (from 21 to 15%), and 35% in both 15-19 (from 17 to 11%) and 20-24 year old (26 to 17%). Surveys of such populations suggest that behavior change might have led to these apparent reduction of infection levels. However more rigorous behavioral and social data will be required to help interpret these trends and to establish to what extent they are related to prevention efforts and/or structural transformations.

Asia

This region ranges from India in the West to China and Japan in the East. It is home to over 60% of the world's adult population, hence what happens in this part of the world will have a major impact on the global pandemic.

There has been substantial variation in the timing and rate of growth of epidemics. In some countries, e.g., Cambodia, India, Myanmar and Thailand, HIV spread has been extensive with extremely rapid growth in some geographic areas. In others, e.g., DPR Korea, the Republic of Korea, the Philippines and Singapore, only limited spread has occurred to date and the rate of growth appears to be considerably lower.

The epidemic in Thailand is among the best documented, with an estimated 750,000 persons living with HIV/AIDS. Nationally, about one third of injecting drug users and brothel based sex workers were infected in 1994. Infection levels in males measured at STD clinics grew from 0% to 8.6% in the first half of the 1990s. HIV prevalence in women attending antenatal clinics rose steadily from 0% to 3.3% over the same time period. This trend is expected to continue for several years. However, there is evidence that prevention efforts are taking effect: HIV infection levels in military conscripts have dropped from 3.6% in 1993 to 2.5% in 1995.

In India there is great geographic variation with high seroprevalence in the South and the West. For example, in Bombay, prevalence went from 2 to 3% in STD clinic attendees before 1990 to 36% in 1994, and infection rates in commercial sex workers rose from 1 to 51% between 1987 and 1993. Women in antenatal clinics tested positive at a 2.5% rate in 1994. Injecting drug use has been a major problem in Manipur state with prevalence reaching 60% by 1992. At the end of 1994, WHO estimated that 1.75 million infected persons were living in this country, while evidence suggests an estimate of over 2 million in mid 1996.

The epidemic in Myanmar is one of the most serious in the region with half a million people with HIV in 1996. It began with the infection of large numbers of injecting drug users in the late 1980s. Infection rates in pregnant women are varying according to region between 0 and 12%. In Cambodia the data indicate that the current extensive spread of HIV/AIDS started during the late 1980s or early 1990s and is predominantly occurring among heterosexuals. In other countries, viz. Malaysia and Vietnam, the rapid growth in prevalence among certain populations during the last 3 years is similar to that seen in Thailand and Myanmar in the early stages of their epidemics.

In China the majority of reported HIV infections and AIDS cases have been among injecting drug users in Yunnan province. There are indications that the virus is spreading now among heterosexuals in the southern part of this country. Official estimates affirm that the number of HIV-infected persons grew to 100,000 by the end of 1995.

In the Philippines the growth of the epidemic appears to be relatively slow, with much lower levels of HIV among sex workers (less than 1%). In other Asiatic countries the still fragmentary surveillance limits the assessment of the situation. However, levels of other STDs seem to be high in their populations implying a strong potential for extensive HIV spread.

The HIV/AIDS epidemics in most countries of Asia have been strongly influenced by gender inequality and the frequent practice of men visiting sex workers. Sharing of needles among injecting drug users has also played a significant role early in the spread of HIV, particularly in the Golden Triangle region.

The scope and efficacy of prevention programmes have varied greatly from country to country. In Thailand a national multisectoral effort was successful in the commercial sex sector, where condom use is now the norm. As a consequence of these behavioral changes STD rates and HIV incidence in younger men have fallen considerably. On the other hand there has been only limited success in slowing HIV transmission between discordant married couples. Thus, infection rates found in pregnant women continue to climb. In India, no formal studies have been done on the large scale impact of prevention programmes, however it appears that fear of acquiring HIV has risen among the educated and the higher socio-economic classes. This may lead to higher condom use, given that these social sectors are disposing of the necessary resources. Unfortunately, in the lower socio-economic classes and rural areas there is still a gross lack of awareness and knowledge of HIV/AIDS, which means that behavioral change has probably been minimal.

Because the epidemics in the region are comparatively young, many doctors fail to properly diagnose AIDS and, in addition, medical care is often unavailable or limited. As a result, the little data which are available, show a shorter survival time after diagnosis with AIDS than in the industrial world.

Some governments have committed extensive resources to responding to the epidemic, but the majority is relying too much on external financial support. Moreover, denial and reticence about releasing information continue to be serious problems.

Latin America and the Caribbean

In this region there is a tremendous amount of variation in the level of HIV spread and the speed of the epidemics among subregions and countries. While the overall rate of new infections seems to increase more slowly than in other developing regions some countries of the Caribbean and Central America are among the most affected world-wide.

The dominant modes of transmission also vary from one country to the next, ranging from some epidemics that are predominantly related to homo- and bi-sexual behaviors, to epidemics connected to injecting drug use, and to others that are primarily determined by heterosexual transmission. In spite of this epidemiological diversity the available data indicate that the pandemic is growing and progressively affecting heterosexual populations and non-urban areas.

Slowly but steadily the pandemic is taking hold of communities rendered doubly vulnerable due to their socio-economic disadvantage and lack of information. Migration, both within and between countries, creates favourable conditions for the spread of HIV/AIDS and hampers preventive measures. The epidemiological evidence signals a rapid shift of new infections to younger ages, particularly toward people between 15 to 24 years old. There are marked tendencies of increasing HIV infection among the general population, especially women and groups which lack basic social, educational and health services. In many sub-regions the epidemics are also associated with a thriving sex industry which includes in several countries the exportation of sex workers and an organized sex tourism. On the other hand transfusion-associated HIV transmission and AIDS cases have drastically declined due to effective blood screening in most countries.

In Mexico there is evidence of continued increasing HIV incidence among men who have sex with men, although the rise is not as rapid as it was in the 1980s. In this country two epidemics are observed: an urban epidemic, more mature and affecting primarily MSM and an emerging rural epidemic which is predominantly spreading through heterosexual transmission.

The Central American Isthmus and the Latin Caribbean reflect epidemics with growing HIV/AIDS incidence and accelerated transmission between men and women. More than half of AIDS cases diagnosed in Central America are reported from Honduras while this country only has 17% of the population. HIV seroprevalence levels among sex workers have reached as high as nearly 40%, and sentinel surveillance of pregnant women in the city of San Pedro Sula has documented infection rates of up to 4%. Patterns of migration and mobility in this subregion suggest that HIV is spreading within each country in well-established local epidemics and externally across international borders.

In the Latin Caribbean, Haiti represents a case of a relative mature epidemic. Mainly due to social, economic and political instability HIV prevalence in the adult population reached in 1994 an estimated 10% in urban zones and 5% in rural areas. High rates of infection levels

found among pregnant women are of particular concern. HIV seroprevalence among Dominican population subsets reached levels up to 11% among sex workers, 5 to 8% among STD patients and, by 1993 1.2% among women attending antenatal clinics. International and intra-regional travel, including tourism and employment seeking, are major influences on the dynamics of the epidemics in this sub-region. Available data indicate growing infection rates among pregnant women, sex workers, applicants for exit visas and migrant farm workers in several Caribbean countries. Some states report AIDS incidence rates that are among the highest in the world.

Within the sub-region of South America, Brazil accounts for 75% of all AIDS cases reported to WHO followed by the Andean Region(15%) and the Southern Cone (10%). There is a considerable transmission of HIV due to injecting drug use in Brazil and the Southern Cone countries of Chile, Argentina, Uruguay and Paraguay. The pandemic in this part of the world has progressed since the early 1980s from one predominated by homo/bisexual transmission to one with accelerated spread by heterosexual contact. In addition, there is an emerging transition from epidemics centered in major cities to increasing involvement of smaller urban centers and rural areas. The impact of the pandemic on morbidity and mortality is already visible where it began first. In the city of São Paulo, for example, AIDS is now the leading cause of death in women of reproductive age.

A significant increase of knowledge about HIV/AIDS has been achieved in most populations of Latin America in the last ten years. Behavior changes are most evident among sex workers, men who have sex with men and among health care providers involved in AIDS management. However, awareness of asymptomatic transmission and of relationship between other STDs and HIV is still very limited. Surveys have documented the persistence of myths, misconceptions and low self-perception of risk.

North America

The growth of the AIDS epidemic in North America has slowed in recent years, largely due to the decline in sexual transmission between men. However, current AIDS incidence is at an unacceptably high level and it must be recognized that this levelling off should in no way be considered reason for complacency.

There has been also substantial variation in the populations affected. In the United States, the increase in new AIDS cases in the 1990s has been greatest for women compared to men, blacks and Hispanics compared to whites, and persons infected through heterosexual contact compared to other modes of transmission. As a result of these trends, in 1995 AIDS incidence was 6.5 times greater for blacks and 4 times greater for Hispanics than for whites, 20% of persons diagnosed with AIDS were women and 15% were infected heterosexually.

HIV transmission continues to occur at an alarming rate and infection levels are high in a number of subpopulations. In 1994, 2.3% of the close to 1 million prisoners in the United States were known to be infected with HIV. Among Canadian prisoners HIV prevalence is higher in women, about 2 to 10% versus 1 to 4% in men.

New infections through injecting drug use continue to take place and the number of users sharing equipment is high, although some studies have shown a decrease of both unsafe injection practices and HIV incidence. In Canada, access to sterile injection equipment for person who continue to inject drugs is available in pharmacies and through numerous needle-exchange programs. In contrast, 45 of 50 states in the USA prohibit the sale or possession of sterile needles or syringes without a medical prescription, and only a small number of legal

needle exchange programs exist. In addition to injecting drug use, the use of crack cocaine has been associated with an increased risk of HIV transmission through sexual contact in both urban areas and the rural South in the USA.

Although there is evidence that HIV transmission through sexual contact between men has declined, younger homo- or bi-sexual men appear to be exposed to a high risk. Frequent practices of unprotected anal intercourse continue to be reported by this age group.

Europe

The complex patterns and dynamics of the epidemics in the European region cannot be reduced to a simple division between eastern and western Europe. However there are large differences in the timing of HIV spread between the formerly divided parts of the continent, and the dramatic socio-political transformations occurring in central and eastern Europe create specific situations of high vulnerability.

Over the past 2 to 3 years, AIDS incidence appears to have stabilized in several countries of the northern part of western Europe. In contrast, in the countries of the southern part of this sub-region there is no indication of the AIDS epidemic levelling off. In central and eastern Europe the HIV/AIDS epidemic is much more recent and the number of AIDS cases is much lower.

Before 1990, most AIDS cases were diagnosed in men who have sex with men. Since 1990, however, injecting drug users account for the highest proportion of yearly diagnosed cases in the region. The shift in transmission patterns is accompanied by an increase in the proportion of female cases, which rose from 11% in 1986 to 20% in 1995.

In western European countries, back calculation models usually demonstrate that the incidence of HIV infection peaked in the mid 1980s. The same method shows a low but steady increase of HIV prevalence among heterosexual populations. Trends for injecting drug users appear more variable and complex. Data suggest that HIV transmission through injecting drug use among young adults decreased in early 1990s in France, Italy and Switzerland, but increased over the same period in Spain and Portugal.

Among the heterosexual STD patients who were not injecting drug users, HIV infection rates were below 1% in 11 countries. Higher rates (between 1 and 3%) were found in France, Germany, Italy, Portugal, Spain and Switzerland. No significant prevalence trend has been observed in the past years.

The lack of basic data means that the change of sexual behavior is difficult to monitor. A review of behavioral surveys carried out in western European countries between 1987 and 1990 shows that the reported number of sexual partners remained quite stable, while condom use increased markedly, particularly for the most sexually active population groups.

Although, until recently, reporting systems had not identified increasing trends of HIV incidence in the general population of eastern European countries, the potential for a rapid change of epidemiological dynamics is of great concern. Large outbreaks of HIV infection among injecting drug users have been observed in the former republic of Yugoslavia, Poland and, recently in cities of Ukraine. Worrisome information is coming from STD surveillance in the independent states of the former Soviet Union, where substantial increases in syphilis rates have been seen since 1990. These results indicate the likelihood of further spread of other STDs including HIV infection. In some of these countries, availability and low income levels

can heavily restrict condom use. In 1995, the price of a twelve unit pack represented nearly one third of the minimal salary in Russia.

North and South Pacific

Australia and New Zealand's experience of the HIV/AIDS epidemic has parallelled that of a number of industrialized countries, particularly those of northern Europe, with the major pathway of transmission being through sexual contact between men and primarily occurring in the early 1980s. This pattern has also been reflected in the French Territories of New Caledonia and French Polynesia. The Epidemic in Papua New Guinea has developed more recently, and appears to involve a major component of heterosexual transmission.

The incidence of AIDS has reached a plateau in Australia and actually appears to be declining in New Zealand. These trends are essentially due to the drop in the rate of sexual transmission of HIV between men that occurred a decade earlier. This decrease began well before any organized prevention program was implemented, but is likely to have been supported through the partnerships developed between gay community-based organizations and governmental institutions. Current tendencies in sexual transmission between men are unclear.

In Australia and New Zealand, HIV infection has remained rare among people who inject drugs, apart from men who also have homosexual contact. In heterosexual injecting drug users, surveys have consistently found HIV prevalence below 2%. Both countries have adopted harm reduction policies, including extensive needle exchange programs. Although the low HIV rates indicate successful prevention efforts in this population, the ongoing hepatitis C epidemic implies a continuing potential for a substantial outbreak of HIV through blood contact among injecting drug users.

In Australia, and to a lesser extent New Zealand, high rates of STDs other than HIV in indigenous people have led to mounting concern about the potential for a major heterosexual epidemic of HIV infection in these populations. Surveillance data to date indicate that the levels of HIV infection is not higher among indigenous than non-indigenous people, but in Australia the rate of HIV diagnosis has increased in the past years among the former. In contrast, the overall rate of HIV diagnosis in the Australian population has declined significantly.

Essential Conclusions

There is evidence that remarkable progress has been achieved in reducing the spread of HIV in some developing countries and in certain populations in industrialized countries. Specifically, the number of new infections has declined in young men in Thailand. A decrease in HIV prevalence has also been observed in young women in Uganda, a country with one of the most mature epidemics. Impressive declines in HIV incidence and/or prevalence have been reported in gay men in the USA, Australia, Canada and Western Europe. HIV infection levels have remained low in injecting drug users in a number of countries. To a large extent, these hopeful trends are attributable to education and prevention programs.

In spite of these singular successes, the HIV/AIDS pandemic continues to expand in most developing regions and among minority populations in a number of industrialized countries. There are also indications of an impending outbreak of epidemics in up to now less affected parts of the developing world and those European countries undergoing political upheaval. Especially dramatic is the growing spread of HIV in young adults, adolescents and children in

developing countries. Rural areas throughout the developing world are increasingly affected. The proportion of infected women is growing constantly and is now roughly equal to that of men in many countries. Globally, heterosexual transmission is responsible for the majority of infections and continues to rise. The social, economic, demographic and health impacts of the pandemic is increasing in most countries.

The global pandemic is composed of multiple epidemics characterised by considerable differences regarding their stages of development, rates of expansion, prevalent transmission modes, affected populations, involved virus strains, among others. Inadequate behavioral and social data make it difficult to interpret the variation in dynamics observed in diverse countries and regions. Research must also be done on societal determinants of vulnerability to HIV/AIDS.

It should be added that the contrast between the ongoing dramatic expansion of the pandemic on the one hand and the successful experiences of prevention programmes on the other cries for intensified efforts to reduce the spread of HIV/AIDS and its impact. Political commitment, international co-operation, a more equal distribution of resources and the active participation of affected communities are required in order to achieve the wider implementation of educational programmes as well as the overcoming of structural factors of risk.

Conference Presentations and Discussions

Introduction

An estimated 15.000 delegates, approximately 2000 journalists and several thousand other visitors came to Vancouver for this Conference. The sheer number of participants made it difficult to organize and facilitate effective processes of information sharing and discussion of relevant issues. Generally, the sessions of oral presentations gave only very limited opportunities for the debate of critical questions. But there were a lot of occasions for initiating personal contacts and direct exchange of experiences in more informal settings, e.g. during poster presentations. The enthusiastic collaboration of numerous volunteers and the natural hospitality of people living together in this multicultural city contributed to reduce the anonymity of such a huge mass event.

Personally, I am not able to make comparisons to former international conferences. People who had attended events of this type before, told me that they observed a wider representation of developing countries regarding both, the topics included and the proportion of participants. While this may be true, I noticed a clear lack of balance between the actual burden of the pandemic carried mainly by the south and the thematic composition centered frequently on experiences gained in and relevant for the north. For many community based organizations, whose representatives could have made important contributions, the prohibitive cost and language barriers made a participation impossible.

However, the absolute quantity of information and arguments relevant to and/or coming from the context of the developing regions was still enormous. Moreover, there are common challenges which are of concern for all who are engaged in AIDS work. The successful strategies and lessons learned in one part of the world may inspire the development of adequate approaches in other regions, provided that the specific settings are reflected and the necessary adaptations take place. Furthermore, an international meeting should be viewed not only as an opportunity for sharing useful information in order to improve local efforts but as a forum aimed at building the indispensable response on a global level. Last but not least, the

universal human right to have access to the best options of care and treatment begins with the access to information. Thus, the following report is a modest attempt to document some results of the presentations and discussions which may - amongst many others - contribute to the dissemination of relevant information.

The division in four tracks (basic science, clinical science, epidemiology and public health, social science) reinforces the still prevailing fragmented views of the AIDS problem and hampers the fruitful meeting of participants with different backgrounds and perspectives, mainly between basic scientists, medical practitioners, PLWHAs, community workers, professionals involved in social research and government officials. Therefore, the thematic structure of this report will differ from the conference format.

Understanding HIV/AIDS as a Global Challenge

Several lecturers analysed the pandemic and the responses to it in the light of current structures and trends of the global society and emphasized the key role of international solidarity. Their critical statements made plain that the theme of the Conference," One World, One Hope", is at best a hope in itself and that we are, sadly, very far from converting it in a reality.

UNAIDS Executive Director stated in his opening address that it is unacceptable that people living with AIDS have to live without the essential drugs they need. He also called for a radical change in the global AIDS research agenda currently determined by the needs of developed countries arguing that ignoring the research needs of 90% of the epidemic is not just unethical, but also irrational.

Eric Sawyer, an activist living with HIV/AIDS, stressed that the hopeful results of new expensive therapies over a short time does not mean that a cure is here. *We are a long way from cure, even for the rich. And for the poor, we're no closer than we were 10 years ago, as long as most people with AIDS can't get aspirin*. He also condemned government officials who want to protect rich populations from the diseases of the poor people by instituting immigration barriers instead of providing health care to the sick. And he attacked drug companies for being more concerned in maximising profits than saving lives. Finally, he called for a global partnership to guarantee access to health care for all people.

Access to treatment in developing countries was also discussed in a satellite symposium organized by GNP+ (Global Network of People Living with HIV/AIDS). This meeting resulted in a set of recommendations including funding mechanisms for subsidizing treatment options, incentives to create local drug manufacturing capacities, the strengthening of technological inter- and intra-regional co-operation, expansion of clinical trials of adequate medications within developing countries as well as the development and enforcement of ethically sound guidelines for clinical research. It was also stated that universal access to health care is an old problem which appears in a new glaring light due to HIV/AIDS. The availability of drugs represents only one aspect of comprehensive health care. Javier Hourcada, a PLWHA from Argentina, expressed emphatically that pills are not enough. *We cannot swallow pills in an empty stomach*.

In another session James Curran, USA, addressed the history and future of the scientific and societal response in the face of AIDS. He insisted on the need to continue and reinforce prevention efforts against the rising tide of general complacency. *We must never accept HIV as inevitable*. He spoke of the importance of social justice to combat the conditions leading to the spread of HIV. His greatest disappointment in the USA is in the area of injecting drug use which is being dealt with not as a disease, but as a moral issue.

In a panel on AIDS, politics and inequality attention was called on socio-economic effects of the globalisation of trade and the connected structural adjustments which are imposed on nations around the world. The resulting aggravation of social polarisation and gender inequalities has increased clearly the vulnerability to the HIV/AIDS pandemic. Poverty and unequal power structures are the strongest predictors of HIV infection world-wide.

In his passionate speech about the future of public health, Jonathan Mann made some impressive reflections on our global ethical responsibility as human beings. The existing divisions within humanity between rich and poor, men and women, infected and not infected are life denying. We need to seek human liberty in the connectedness with one another. The challenge is to build a new solidarity in a world with AIDS which means to link the healing of the world with our own fate. He recognized that the required changes will be threatening the social status quo. The human right approach should form the base of a real global public health strategy. He also deplored the lack of communication between scientists and activists.

A comprehensive exposition of the fundamental approach which can lead us to a clearer understanding of and a more effective response to the pandemic was made by Richard Parker, a social scientist and NGO coordinator from Brazil. He mentioned three key elements of an important change of paradigms which gives some reason for hope in spite of the unabated progression of HIV/AIDS and the still prevailing bureaucratic responses:

- a growing awareness of the complex social, cultural, political and economic causes of the epidemic which goes beyond the notion of individual risk
- a shift from individualistic and information-driven conceptions of education to more multidimensional models of collective empowerment and community mobilisation, and
- a new understanding of the degree to which the struggle against HIV/AIDS is in fact part of a much broader and more long-term struggle aimed at addressing the issues of inequality and injustice.

Recognizing the necessity of long-term social change does not mean that nothing can be done on a short-term basis. Dialogical learning processes as well as structural transformations through joint actions are required. Focusing on the issue of social vulnerability, we have begun to forge a truly global coalition. Politics and science cannot be conceived apart from an ethical framework, rooted in a moral philosophy capable of giving meaning to our work. The essence of human solidarity can be found in our capacity to interpret the pain and suffering of others as our own and, consequently, to take responsibility for the collective effort to change it. The true challenge is to overcome the oppression, discrimination and violence that everywhere can be found to lie behind the apparent shape of the epidemic and to build one world out of many by learning to respect our differences going at the same time beyond them in our common struggle.

Joseph Decosas, a Canadian physician working in West Africa, discussed the complex nexus between HIV/AIDS and development in both directions, HIV/AIDS as a consequence of developmental failures and the pandemic as a threat to development. He identified three categories of co-factors for the spread of HIV which ultimately can all be traced back to characteristics of social development. Untreated genital tract infections which appear as a biological co-factor have to do with the accessibility and quality of medical services, the capacity to pay for the treatment, levels and contents of education and women's autonomy to seek care. Cultural phenomenons like sexual relationships between young girls and older men who are more likely to be infected are also a development issue: When educational and economic opportunities for women improve, the age differences between sexual partners usually decrease. Massive population movements which are well documented as a structural

factor fuelling the epidemic are often the result of ruthless industrialization. He presented a revealing case study from Ghana where HIV infection levels among pregnant women living in the area next to a hydro-electric dam are five to ten times higher than in the rest of the country. The obvious explanation is that after the completion of the dam in the early sixties some 80.000 people were expelled from their land due to the flood. While men became fishermen or migrated in search of work, the displaced female farmers had few choices but to enter prostitution.

With regard to the impact of HIV/AIDS on social development Decosas argued that evidence of a negative effect on the macro-economic level is lacking. Certainly he was right to say that indicators like growth rates of gross domestic product do not reflect adequately the well-being or developmental status of a society. But his historical example of an unexpected outcome, the plague epidemic in medieval Europe, which in his opinion preceded the collapse of the feudal system and the rise of the global economic supremacy exerted by this continent in the following centuries, was probably misleading. The morbidity and mortality of HIV/AIDS is age-specific, killing primarily the age groups which form the main productive force of a society. It is true that this shift in the producer-consumer relation menaces first the economic subsistence of directly affected families, households and communities. Yet, it is likely to reduce the productivity and potential of a national or regional economy on the whole. He recognized this impact with respect to the agricultural sector, when he stated a decline of crop yields and an increase of less nutritious products resulting in a deterioration of people's nutrition status. His final conclusion that HIV/AIDS has become an important factor within the complex interplay of diverse forces which determine the specific course of social development in different countries cannot be contested.

There is no doubt that the degree of commitment shown by political authorities is - apart from internal and external structural conditions - the most important factor to determine the course of the epidemic. The policy of openness adopted by the Ugandan government was cited as decisive for the reduction of new cases of HIV infection now being reported in that country.

Except for these more critical, analytical and comprehensive visions most individual presentations neglected the societal dimension of the HIV/AIDS problematic completely or failed in reflecting their results of behavioral research in the light of a deeper analysis of social relations. This underpins the impression that the understanding of the social, cultural, economic and political forces shaping the course of the epidemic is still incipient.

Risk Factors and Situations

A case control study performed in rural Tanzania collected detailed data on demographical and other risk factors as well as sexual behavior and practices. Having temporarily lived outside of the community and having no or little formal education were found significantly associated with HIV incidence. A history of blood transfusion or the circumcision status in men was not associated with HIV incidence, nor was any particular type of sexual activity.

The high vulnerability of migrant, often socially marginalized populations was also verified through the results of a research done among women living on the Bateyes (settlements) of large private sugar cane companies in the Dominican Republic. These women have a five-fold higher risk for HIV infection than that for the female population of this country in general. Unequal sex ratios and lack of economic opportunities for women in the sugar cane industry make formalized prostitution and informal exchange of sex for money common survival strategies. Nevertheless 46% of seropositive women reported only one or two life-time partners. For women born in neighbouring Haiti (more than half of the studied sample), those

coming to Dominican Republic alone or with a relative were more likely to be infected than those coming with a male partner. High prevalences of cervical and vaginal infections were also found in this female population. Organizers of a project collaborating with Hispanic female farmworker groups in California and Texas mentioned recent studies which show that HIV infection rate among migrant and seasonal farmworkers may be as much as 10 times the national rate.

A presentation from South Africa informed that 95% of the country's gold miners are living in single sex hostels away from their families. Given the easy availability of alcohol and commercial sex, the conditions for the rapid spread of HIV are ripe in this population.

Some of the presented data provide empirical evidence of the close relation between socio-economic disadvantage and vulnerabilty to HIV/AIDS, leading to an increasing "pauperization" of the epidemic. In Brazil, for instance, of the AIDS patients reported in 1995, 70% were illiterate or had attended at most elementary school, while at the beginning of the epidemic more than 80% of all cases had at least secondary education. A study carried out in a public health service which offers anonymous testing in São Paulo detected that educational level less than complete high school was significantly associated with HIV infection among nearly 4.000 women who returned for their test result. The information system established in the state of São Paulo to provide epidemiological data on asymptomatic patients followed in the public health services calculated that the educational level of 74% reaches at most elementary school. Only 3% of the women and 6% of the men had a specialized occupation or were the owners of a business. Of the 142 women who were attended since 1990 in a hospital in Rio de Janeiro more than 90% came form outlying poor areas of the city.

Findings from 17 different studies conducted by the International Center for Research on Women in 13 developing countries reveal that many adolescent and adult women have been forced to have sex and hesitate to discuss infidelity and condom use for fear of a partner's violent reaction. Fostering linkages between AIDS initiatives and the violence against women movement, advocating for legal reform or monitoring existing laws, ensuring that messages of condom promotion do not capitalize on macho or aggressive behavior were mentioned among others as necessary strategies to confront this violation of women's physical and mental integrity which is closely associated with vulnerability to HIV/AIDS.

A study from Vitoria, Brazil, corroborated the fact that many women are at risk of HIV infection due to the behavior of their steady male partners. Of 84 HIV positive women that received medical care in a public clinic during the past three years close to 60% had only one partner.

The relation between living and working conditions and an unhealthy life-style was highlighted by research with truck drivers in India. Separation from their families, passing sleepless nights behind the steering, lack of recreation alternatives, among other problems make excessive intake of alcohol with peers and visiting nearby brothels their prime diversion.

Knowledge, Awareness and Attitudes

Many experiences evince a wide gap between an apparently satisfactory information level and a general conformity with prevention norms shown by common studies on the one hand and the persistence of behaviors and practices that put people at risk of HIV infection on the other. The complex, socially mediated process of interpretation of informational inputs and the resulting translation in practical conduct is still poorly understood and frequently overlooked in the planning of preventive measures.

A study on rural communities in Vietnam using a qualitative, focus group methodology concludes that officially sanctioned policies about HIV/AIDS are superimposed on traditional beliefs and norms without changing them. These deeply-held attitudes are generally not detected by quantitative studies but come to light with qualitative investigation. Specifically, it was found that rural men commonly frequent hostess bars where sex is available, and many rural men have minor wives. Rural women accept these behaviors, and both sexes see little risk of AIDS because the sexual partners are not considered prostitutes and the men are not considered "bad husbands". Condom use was low, especially among younger people, and mainly related to family planning. Despite many HIV infections in rural areas, most respondents do not believe that there are persons living with HIV/AIDS in their own province. The majority relies on the government to prevent AIDS by controlling prostitutes and drug users in major cities.

A qualitative study among rural adolescents in Mexico found that, generally, migration is a space where sexual initiation takes place, outside of community norms and without barrier methods of protection. There is a fundamental differentiation based on gender. While sexual decision-making and expression of girls is inhibited by social control, young men are encouraged to have sexual relations as part of the rites of passage into adult life. Sexual initiation is pushed by relatives or peers and commercial sex is one of its principal routes.

A synopsis of household surveys done in 18 countries, mainly in Africa and Asia, which used face-to-face interviews to investigate sexual behavior, observed a huge variability with regard to the proportion of men reporting sexual contact outside regular partnerships in the last year ranging from 4 to 47%. Contacts with sex workers ranged from 1 to 25%. Women were much less likely to report non-marital sex than men. Condom use was very low in most study sites. Yet, inter-country differences may, to some extent, be artificial reflecting actually the context-specific readiness to talk openly about intimate facts and admit engagement in socially less accepted behaviors. Besides controlling for these influences on data inquiry there is a necessity to investigate social and cultural determinants of existing differences.

The fact that results of sexual behavior research depend highly on methodologies used was verified by comparing studies done with women in different countries. For example, when surveyed 8.6% of young, unmarried women in Mauritius reported having had sexual intercourse. On the contrary, in-depth interviews with a similar population showed that 20% were sexually experienced. Qualitative, participatory methods also uncovered other risk behaviors which would not have been detected by a survey. Involving the community in instrument design, data collection and analysis, and program planning produced not only valuable results for research, but catalyzed also community responses.

The effect of culturally defined perceptions of sexual risks on behavior was explored by an investigation with young people of different socio-economic background in Sri Lanka. While knowledge of AIDS and HIV transmission was relatively good, the findings indicate much greater concern about sexuality leading to loss of virginity, marriage ability, pregnancy, loss of reputation and family awareness of sexual activities. Their efforts to resolve increasing sexuality with avoidance of these perceived problems include on the one hand abstinence and practices that emphasize non-penetrative sex, but on the other risky behaviors like anal sex, male visits to female sex workers, young males having sex with older women and sex between men.

Another interesting example of the strong and complex influence that specific socio-cultural identities exert on personal decisions about risk taking and self-protection came from a research which conducted in-depth-interviews with female sex workers in Mexico City. These

live in a constant double bind, playing roles considered to be opposites - mother and "prostitute" - and are profoundly affected by society's double standard for women. The separation of their two identities or lives is created and sustained through images, rituals, symbols and myths. Condom promotion in commercial sexual contacts serves as a physical and symbolic barrier between the professional and private life. Correspondingly, condom use is rejected in private sexual relations, a fact which needs to be targeted in culturally appropriate prevention programs.

Most of the misconceptions referred to by diverse presentations are related with the fatal myth of risk groups and the incomprehension of asymptomatic infection. Discussions with diverse social groups in Laos found that protective behaviors included condom use with commercial sex workers, but not with "non-professional" girls or women. One common perception about HIV/AIDS is that person who appear "clean and plump" are not infected and unprotected sex with them is safe. A study carried out with overseas contract workers from the Philippines showed that three quarters correctly defined HIV and AIDS, but most of the respondents thought HIV exposure to lead immediately to AIDS and more than half believed all seropositives to be symptomatic.

The appalling lack of knowledge and awareness still prevailing in many regions of the world even in more literate populations was shown by a study done in Madras, India, which interviewed 40 women working as trainers in programs like family planning , adult literacy etc. and wanting to integrate AIDS education in their existing projects. 83% believed that AIDS could be cured. 91% felt infected persons could transmit the virus through social contact and they should be isolated. Only 31% thought that multiple sexual relations involve a risk of infection and as few as 22% were aware that proper condom use reduces the risk of transmission.

An extremely low awareness of AIDS and methods of protection against it was also found among Dai ethnic minority villagers in China's Yunnan province bordering Laos. Only 18% of 177 persons surveyed in 1994 had heard of AIDS. Among those who had about 40% did not know one of the main transmission routes. When condoms were shown to focus group participants, most said they never had seen one before and very few were aware that condoms can be used for protection from STDs.

Impact of the Epidemic

Based on the 1991 Ugandan Census, one presentation described the effect and geographic extent of HIV mortality on population structure in this country. There were notable demographic impacts at the parish, but not yet at the district or national level. The very severely affected parishes had 27% population deficits, with 50% deficits in males aged 40-44 and females five years younger. Consequently, at the beginning of this decade the impact was very localized and correlated with areas of early, high HIV prevalence. At present, however, it may have intensified and extended geographically.

According to a study conducted in 1993 and 1994 in the Philippines, the medical care costs of AIDS exceeded the average per capita income of a Filipino household. Since there was very limited insurance coverage, these costs were borne either by state institutions or the families. Of the 54 patients interviewed, 18 (33%) lost employment immediately after diagnosis and another 15 (28%) changed occupation. Similar problems resulting from discrimination and profit orientation of employers were reported from São Paulo, Brazil, where half of 26 interviewed women with HIV infection faced important changes in their jobs after diagnosis and most of them were still out of work.

A study conducted in Rakai District, one of the most affected areas in Uganda, involved a representative cohort in which 22% of adults were HIV infected. Of all children below 15 years 4.5% had a deceased mother, 7.9% had a deceased father and 2.4% had lost both parents. Although about half the parental deaths were AIDS related, the rate was about 65% in children below 5 years and 35% in those 5-15 years. Family incomes in homes with orphans were generally lower than those in other households, partly because many are headed by females - 62% compared to an average rate of 30%. Nearly two thirds of households with AIDS related deaths reported selling property to cover medical treatment and burial costs. School attendance is lower for orphans, especially girls, being 47% in girls and 67% for boy orphans.

An investigation on the coping mechanisms of families in response to HIV disease performed in the Philippines concluded that the low income groups have no margin to absorb AIDS related costs resulting in increased social inequity. Poor families even sold clothes and household accessories to finance medical care. Other coping mechanisms included care by immediate members of family incurring in absence from work and increased labour participation of women and elder children.

Assessments of socio-economic impact is beginning to include gender as a category of analysis. On a household level, male infection may lead to a greater loss of income, while female infection may result in significant drop in food availability, nutrition and household management. Particularly in Africa, where women produce 60-80% of agricultural outputs, increases in female seroprevalence could seriously affect agricultural production and nutrition.

Change of Attitudes and Behaviour: Strategies and Barriers

Naturally, numerous studies and experiences during the Conference attempted to explore the factors associated with success or failure of education programs aimed at the prevention of HIV transmission and/or the reduction of discrimination against affected people. The majority did not reveal completely innovative results, but the confirmation and documentation of relevant insights may guide the planning of interventions and convince potential opponents.

A study conducted in seven training sites in the USA assessed the impact on health care providers who attended educational programs finding that including panels of PLWHAs produced greater change of attitudes, viz. reducing fear of contagion and increasing acceptance of homosexuality. An evaluation of an Australian project which trains and promotes persons living with HIV/AIDS to speak about their experiences to different audiences, especially high school students and health care providers, noticed a high degree of satisfaction with the talks among the participants. Personal narratives were seen as powerful educational tools which present the reality of living with the infection, "humanise" the statistics of the epidemic, provide a catalyst for discussion of difficult issues such as sexuality and reinforce prevention messages. By not setting themselves up as "living warnings" speakers enabled an identification and helped to overcome the perception of AIDS as a distant possibility affecting others.

A contribution from UNDP stated that the importance of the inclusion of people living with HIV/AIDS and groups most affected by the epidemic in policy development and implementation has been demonstrated. This participation can be encouraged and facilitated by community based networks which also play a role in support and advocacy on behalf of disadvantaged populations.

Many presented experiences confirmed the positive results of the participation of peer educators in the planning and development of information and prevention programs, even in

adverse circumstances and targeting extremely marginalized groups. A project which includes street involved youth as peer educators for the dissemination of information on STDs and HIV found that these achieved a very good acceptance and credibility. A harm reduction program established in New Delhi, India, with IDUs from a socioeconomically deprived background integrates in its staffing rehabilitated ex drug users as peer educators considering them a key factor for achieved successes in reducing risk practices and motivating for detoxification. The evaluation of a project targeting men who have sex with men in Madras, another town in this country, concluded that the outreach activities of credible peers proved effective in influencing this population to adopt less risky sexual practices. Assessments of several programs carried out in the USA, which involved active drug users to educate their risk networks, found that peer involvement is essential to maximize efficacy in promoting needle hygiene. The mentioned advantages include identifying and recruiting drug users by those with the best current information, performing preventive efforts in terms that are culturally appropriate to each user group and cost efficiency. A project working with sex workers in Francistown, Botswana also found that peer education can be helpful in hard-to-reach groups particularly when using a participatory approach. Recent epidemiological data from the Dominican Republic showing lower syphilis and gonorrhoea rates among sex workers in several STD clinics are attributed to prevention programs carried out by peer educators. A project targeting truck drivers and petty sellers (male and female) in motor parks in Nigeria works with the leading idea that people are more prepared to listen to someone like themselves than an outsider and that the peer group approach overcomes concentrating on mere knowledge by emphasizing self help and participation.

The effects of a peer-led HIV prevention program on the initiation of sexual activity among multi-ehnic high school students was evaluated in urban areas of California. Students in the intervention school received basic sex and drug education taught by health educators, followed by interactive sessions conducted by older peers, which focused primarily on peer norms, skills building and motivation to remain abstinent or have only protected sex. Control school students received a standard AIDS and sex education curriculum. Students in these comparable schools were surveyed regarding sexual behavior prior to the intervention and during the following grade. Of the control students, 18% initiated vaginal intercourse during study period compared with 5% of students in intervention schools. The latter also developed safer sexual norms, while control student's norms became riskier. A peer education program for public high school students in Davao City, Philippines, also presented its lesson learned that students themselves are the best AIDS educators to their fellow students for they know best the sexual behaviors and needs. This approach encouraged genuine openness and candidness among students.

An education project directed towards rural populations in southern Mexico experienced a kind of scepticism regarding AIDS unless people have had contact with the disease before. However, the use of native culture and traditions of each community has been helpful to spread relevant information, especially when illiterate people are targeted.

A better understanding of factors which influence sexual decision-making is essential for the development of effective prevention efforts. Focus group discussions conducted with women (90% African American and Latina) residing in communities with high HIV incidence in New York City identified some psychological obstacles for condom use and the adoption of other safe sex practices. Most participants reported that they would not ask a "steady partner" to use protective methods, citing the need to demonstrate love and trust, often in the face of knowledge of partner's past or current risky behavior. It was concluded that perceptions of romance and intimacy hindered self-protection among these women despite their characterisations of steady relationships as episodes of "serial monogamy". Possible

backgrounds of these illusory feelings related eventually with the idealization of gender roles and models of relationship were not discussed.

A research carried out with Brazilian women of low income groups concluded that most of them place their family relationships above all else, and feel that they cannot afford behavior changes that may put this in jeopardy. To even suggest safer sex appears as a threat to the family context and may tarnish her identity as a "respectable women", a highly valued and hard won attribute that extends far beyond mere economic survival. Generally, the "other woman" was blamed for the HIV/AIDS problem.

Compared to its outstanding importance, few presentations addressed the consideration of gender relations in program design. A prevention project implemented in Bombay, India, draws the general conclusion that gender sensitivity must feature in all educational efforts and that there is a need to sensitise the male population too, for raising the concern about the vulnerability of women. Experiences gained in the Philippines, as in many other countries, imply that STD/AIDS control policies dealing with sex industry should also address men as customers, rather than focusing solely on sex workers as a "risk group". Personal interviews with sex workers, clients and pimps as part of an evaluation of a behavioral intervention in Bali, Indonesia, found that STD knowledge of clients had the largest effect in increasing the efficacy of educational sessions. Interviews conducted with Ugandan women whose husbands had received a diagnosis of HIV infection showed that 85% were financially dependent and three quarters of them did not feel at risk of HIV infection. Only 12% had discussed condom use. Low risk perception, financial dependence and poor communication skills were discussed as essential points of prevention programs, but the task to target men was not mentioned. A peer education project working with adolescent factory workers from northern Thailand presented their experience that women are more able to converse, express opinions and ask questions with regard to HIV/AIDS in female groups, because they face greater social losses than men if they discuss sexual health in public. Their perception of risk and options for prevention improved, but girls said communication with boys was difficult and males needed peer education about reproductive health as well. Mixed groups were successful when peer leaders and participants knew each other well before intervention activities. Mixed peer leader/educator training was highly effective because girls had the opportunity to converse with boys in a controlled environment.

The results of a research conducted with street youth in South Africa demonstrates that these children are drawn into different kinds of non-consensual sex as part of their low status. In these encounters, individually directed risk prevention strategies based on rational choice models of decision making and action are extremely limited. The vulnerability of street children reveals the need for broad-based social interventions to overcome social conditions and relations which force poor women and children to merchandise their sexual capacity.

A presented overview on the preventive effect of syringe exchange analysed data from research conducted in North America, Europe, Asia and Australia where HIV incidence among participants was measured or could be estimated. The vast majority of studies (14 of 16) showed low rates of transmission of blood-borne viruses. In the two studies with apparent high rates of HIV incidence possible causes include multiple risk factors among drug users as high injection frequencies, high sexual risk behavior and manifold social disadvantages, and policies that limit secondary distribution of syringes. Increasing use of bleach for cleaning of injection equipment was presented by a program from Manipur, India, as a viable option in settings where availability of needles cannot be improved within short time because of economic and political reasons. Among the target group of 790 injecting drug users an increase of bleach use

from 30% to more than 70% was reported as a result of an outreach intervention through trained ex and current drug users.

Only few project presentations took into consideration the wider socio-political framework and its influence on the outcome of prevention efforts. A sex workers outreach project performed in the Australian state of New South Wales stated that a progressive approach to law reform and a supportive environment empowers the target population to take care of their health and that of their clients. The legalization of sex work and the co-operation with police has allowed to produce and distribute educational resources. Approximately 95% of sex workers demand the use of condoms in all sexual encounters. However, condom use is lower amongst illegal migrant workers. This setting has contributed to low rates of HIV/AIDS and STDs. An opposite example was cited from a support organization working with male, female and transgendered prostitutes in Porto Alegre, Brazil. In this context police violence, poverty and consequently low self-esteem among sex workers pose serious obstacles to AIDS/STDs prevention programs.

However, strategies to build the necessary bridges between the implementation of specific projects in AIDS prevention and care on the one hand and the fight for the rights of people affected by and vulnerable to the pandemic on the other did not make up a focus of the contributions. Thus, two essential questions pointed out by Jane Galvão, coordinator of a Brazilian NGO, remained unanswered:

- What can we do to avoid falling into the passive routine of administrating initiatives that already exist, and giving up the chance of questioning in depth the world's health policy?
- What should be done so that the many institutions that are currently financing AIDS-related activities stop seeing the community groups and NGOs as simple executors of projects and begin to understand the political dimension that to a large extent is what lends sense to the existence of these groups?

HIV Transmission

The factors which influence the infectivity of HIV seropositive individuals are poorly understood. A study conducted in Abidjan, Côte d'Ivoire, analysed cervico-vaginal HIV shedding in female sex workers infected with HIV. This indicator of infectiousness was more frequently detected in women with HIV-1 compared with women living with HIV-2, which may explain the greater transmissibility of HIV-1. HIV-1 shedding was also significantly more frequent in female sex workers with immunosuppression, with a cervico-vaginal ulcer or an sexually transmitted infection. Another research involving female STD clinic attenders in Mombasa, Kenya, found that endocervical shedding of HIV-1 was correlated with use of oral contraceptives, injectable progesterone, gonococcal cervicitis and CD4 lymphocyte depletion. The data of an corresponding study on determinants of HIV shedding in semen of seropositive men performed in Seattle, USA, suggest that declining immune competence was an important predictor of detecting HIV RNA. Another research conducted in Malawi found that providing effective antibiotic treatment to men with urethritis resulted in a rapid reduction of seminal HIV. Confirming former epidemiological observations, these results permit the conclusion that increased infectivity is associated with disease progression and the presence of genital tract infections. Likewise, they underpin the preventive effect of STD treatment. Recent analyses suggest that infectiousness may also be increased substantially in the brief primary infection phase. Yet, additional research should be undertaken to better understand sexual transmission of HIV and to help formulate prevention policies.

Mother-to-child transmission of HIV was analysed by several investigations in relation to factors as maternal clinical status, mode of delivery and breast-feeding. The common conclusion is that those children born to symptomatic mothers and/or breast-fed have a higher risk of acquiring the HIV infection. In a study done in Rio de Janeiro, Brazil, of the 105 children born to seropositive mothers, the rate of HIV transmission was 33% in the asymptomatic mothers group, whereas it reached more than 62% in the group of symptomatic mothers. Nearly half of the children who were breast-fed were infected, whereas only 19% of the bottle-fed children seroconverted. Similar data came from a research carried out in Soweto, South Africa, where in a sample of 163 mother-infant-pairs 46% of the breast-fed children were infected as compared to 18% in formula-fed infants. In the breast-fed group 15% of transmission occurred after 6 months of age. It appears that breast feeding by HIV infected mothers may be one of the factors determining the high rate of vertical transmission of about 40% in developing countries. The results of a research conducted at a tertiary hospital in Blantyre, Malawi, using polymerase chain reaction to detect HIV a short time after delivery suggest correspondingly that a non-negligible proportion of children not infected during gestation and delivery acquire the virus postnatally by breast feeding. However, the investigators also recommend to perform a careful risk-benefit-analysis before any changes in established breast feeding policies are considered. In the Brazilian study the percentage of transmission was slightly lower in those children delivered by the vaginal route (38%) in comparison with children delivered by cesarean section (45%).

Women Controlled Barrier Methods of STD Prevention

With regard to microbicide containing gels safety studies are necessary because irritation of vaginal and cervical mucosae has been associated with spermicide use which might enhance the risk of HIV transmission. The results of two presented double-blind placebo controlled trials to determine the safety and tolerability of intravaginal nonoxynol-9 in a gel formulation were contradictory. The first study carried out with 60 female sex workers in Mombasa, Kenya, instructed to use the gel once daily during 2 weeks did not detect differences in the incidence of ulceration or abrasion by visual or colposcopical examination. The second trial conducted with 40 female volunteers in London, UK, who were recruited and randomised to use the gel every night for one week found histological signs of inflammation in 35% of the nonoxynol-9 group and 10% of the placebo group. In five subjects (all in the nonoxynol-9 group) there were both colposcopic and histological evidence of inflammation. This presentation drew the conclusion that histological findings suggest a biological mechanism to underpin the observation that use of high doses of nonoxynol-9 may potentiate HIV transmission.

Care

Several presentations addressed the potentialities and limitations of home care for people with AIDS, which represents the predominant organisational response in most developing countries to increasing needs of caring for chronically ill persons. An experience from Zambia showed that the majority of patients (77%) and immediate care providers (71%) preferred the care to be home based. But a high proportion of chronically ill persons perceived the care they received as rather restricted and frequently inadequate. Despite the willingness of relatives supporting in various ways, most care givers experienced critical problems related to food provision and proper hygiene.

Assistance approaches which go beyond a narrow health care model including education on HIV prevention and AIDS care, addressing financial and social support needs as well as strengthening community structures and social networks of PWAs were found very helpful in

different countries. The Health Promotion Center, the home-based care section of the Church of Christ AIDS Ministry in Thailand, observed an increasing acceptance of PWLHAs within families and communities. Its teams which offer education and holistic support through home visits have been well received by affected persons as evidenced by the increasing number of people who request visits. A project developed in Malawi to deal with the impact of AIDS in populations with a poor socio-economic background highlighted the importance of incorporating the strengths of the community rather than merely focusing on problems. This strategy changed the image of volunteer counsellors from being "messengers of death" to respected and welcomed facilitators of knowledge and support leading to a greatly enhanced community mobilisation. Another project in Mexico uses the methodology of popular education to develop training, orientation and support activities with care givers including family members, partners and friends. The assisted persons (more than two thirds were women) have shown greater confidence and security on living with and caring for their relative or friend with AIDS. The combination of skill-building and community sensibilization helped PLWHAs to come to terms with their HIV status and improve their quality of life and to avoid burnout of caregivers. It was noted that, as seen in many cultural contexts, women are entrusted with the provision of care.

A study conducted in the Dominican Republic compared the impact of two approaches to health care on health behavior, health status and psychological well-being of persons living with HIV/AIDS. The Ambulatory mode included AIDS education, monthly medical checkups and group therapy for patients. The Household mode comprised transferring nursing skills to HIV positive individuals and their families at home. The Household care was more effective in preventing health crises. It reduced more the needs for hospital admission and lowered medical expenses. Social relations remained more stable than in Ambulatory care. Recommendations for action were more realistic, complete, and adjusted to family resources. Participation of family members was more active and effective. Support was more efficiently mobilized. Finally, skills were generalized to other health crises.

A research that interviewed persons living with HIV/AIDS and their family members in Mumbai, India, with a special interest in the gender dimension of household responses concluded in the sentence that "men receive care and women provide". Although responses of relatives were found to be largely positive, a strong gender bias was observed in favour of men and against women with HIV. As primary givers, women were not assured of home care for themselves. Widows and unmarried women with HIV were particularly affected. Needs of seropositive women therefore require special attention in AIDS programs in this country - and probably in many others.

An investigation conducted in Mexico revealed the common existence of hidden agendas of those involved in care for people with HIV/AIDS. Support was often activated by interest in goods of infected persons or because it helped to keep the case secret.

A study of attitudes and opinions of medical staff in northern Thailand found that refusal to take care of AIDS patients was rare, although perception of risk of acquiring HIV infection through this work and feeling that it required great self-sacrifice was frequent. Most thought that AIDS patient care was an unnecessary waste of resources since a cure is unlikely. Many respondents felt that nosocomial transmission of HIV to other hospital patients was an important problem and mentioned separation of AIDS patients as a solution.

The influence of living and housing conditions on disease progression was studied by a charitable medical clinic in Rio de Janeiro run by the Catholic Church comparing the survival time from the date of AIDS diagnosis to the date of death of three different groups of patients

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who were seen by the same team of doctors and had access to the same treatment. The category of currently homeless persons had a mean survival of 8.2 months, while this time period reached 17.8 months in ex-homeless patients staying in a support house and 18.3 months in people living with relatives belonging to the poorest section of society.

Pathogenesis and Therapy of HIV Infection

In the 2 years preceding the Conference new tools for laboratory diagnosis and antiviral therapy were developed which have made possible important advances in understanding the biology and treatment of HIV. Preliminary experiences with the resulting novel therapeutic options have raised a sense of hope, at least among practitioners and patients who have access to them.

One of the relevant developments refers to the way the extent of the disease is defined. Until recently, monitoring of HIV progression was based on CD4 lymphocyte counts, which could only measure the damage already occurred. Now, new molecular techniques are available to quantify viral load, the amount of virus particles floating in blood plasma, as an indication of how fast the virus is reproducing and threatening healthy immune cells. Several presented clinical trials confirmed that this plasma HIV RNA measurement is an earlier and stronger predictor of long-term disease progression and mortality risk than the number of CD4 cells, i.e. a high level of viral load is associated with a higher risk of negative outcome. Very low levels define persons with a high probability of becoming a long-term non-progressor. In addition, it is considered a useful indicator for guiding the initiation of therapy and assessing the response to it.

Early pathogenesis studies and the ability to better quantify plasma HIV load have established the extensive, persistent and dynamic nature of HIV infection. Prior beliefs, based on the concept of a prolonged phase of relative virologic latency have been replaced by a new paradigm of ongoing, high-level viral replication from the time of initial infection until death. After primary infection an explosive multiplication is taking place which is subdued partially by the immune reaction until a set-point is reached in the course of the first 6 months. This level is interpreted as a steady state explained as a dynamic balance between immune response on the one hand and the viral multiplication and mutation on the other. Research teams deduced the kinetics of viral replication before treatment and calculated the rates of production and clearance of CD4 cells in the presence of HIV infection. Minimum estimates suggest that every single day 10 billions virions are produced and cleared by the immune system of an infected person. Likewise between 1.8 and 2.6 billions CD4 cells are produced and destroyed. The overall replication cycle is about 2 days which means that 180 virus generations are produced per year.

Closely connected with the advances described above is the development of new classes of antiviral drugs. Besides other reverse transcriptase inhibitors, which block in different ways the enzym necessary for the translation of viral RNA in DNA, the biggest innovation is the whole group of drugs aimed at an entirely different target: viral protease. This substance regulates the final maturation process of viral structure required for its infectivity. The combination of therapeutic agents with divergent mechanisms of action permits the interruption of replication cycle in different stages. At present, several combination regimens are explored for their immunological and clinical efficacy, and available data show substantial reduction in viral load. In many cases the suppression of viral replication is so profound that the virus is no longer detectable with currently available techniques. Lecturers also reported that clinical benefit was achieved as disease progression decreased and survival increased. These facts gave rise to the

hope that the emergence of drug resistance can be prevented overcoming the basic problem of former treatment approaches. Some investigators spoke even of the possibility to eradicate the virus through a completely inhibitory treatment regimen administered for 1.5 to 3 years.

However, there were also voices of reservation and caution. Clinical experience with protease inhibitors only dates back 16 months, so there is no way to know what physiological impact and possible adverse side effects these drugs will have over a longer period of time. A reduction in plasma viral RNA to levels that are below those detectable by current techniques does not necessarily reflect complete suppression of viral replication. It remains doubtful whether suppression can be maintained for a sufficient period of time. It was also mentioned that sucess will depend on there being no viral sanctuaries which drugs cannot penetrate. Combination therapies also require an enormous precision and discipline on the part of patients considering the fact that multi-drug resistance will occur almost immediately if treatment is interrupted.

Whether a medical solution is really at hand will become more clear in the next years. However the main question lies in the extremely high cost of new treatment options in the face of a steadily growing disease burden in the poor regions and communities of the world. Expenses for drugs for combination therapy amount to about US$ 15,000 to 20,000 annually per patient. During the Conference, protests were organized against the price policy of drug companies. Even if a reduction could be achieved, the vast majority of people living with HIV/AIDS will remain excluded from advances in clinical science as long as the extremely unequal distribution of resources persists, and per capita health expenditures of many developing countries do not exceed a few dollars per year. A priority concern for the future will be to avoid that governments lower their international co-operation for preventive efforts rather than strengthen it, in the illusion that the pandemic is under control with the advent of a medical solution.

Sources: Abstract Volumes, Daily Progress, different available papers, own notes taken of presentations and discussions.

2

MATERIAL ON HIV/AIDS

SENT BY

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XI International Conference on AIDS, Vancouver, Canada, 7-12 July 1996

One World. One Hope

For the first time in 6 years the International Conference on AIDS returned to North America. Set against the magnificent back-drop of Vancouver (surely one of the world's most spectacularly located cities, with its bustling harbour, pristine waters, verdant hills and snow-capped Rockies) some 15 000 people gathered to attend what the Canadian newspaper *The Globe and Mail* described as one third carnival, one third medical expo and one third science. A harsh comment, maybe, but the conference did provide the usual heady mix of science, medicine, development issues, trade show, politics, protest and culture. Former presidents of state, European Ministers of Health, generals from armed forces, leading scientists, Elizabeth Taylor ("it has been a long time since I visited an international AIDS conference") all participated in the conference alongside people with HIV and AIDS, prostitutes, NGOs and intergovernmental organizations, charities, community workers, researchers, clinicians, representatives of the pharmaceutical industry and publishers. Protests highlighted the fact that the USA still has not changed its immigration policies (the reason for the 1992 conference being held in Amsterdam rather than Boston as originally scheduled), that the Canadian AIDS strategy is, at best, inconsistent, and that inequity continues. Care was needed to identify and sort out the various agendas behind the rhetoric; ACT-UP protested about the lack of access to drugs in the developing world and scientists sponsored by pharmaceutical companies were advancing the idea of a cure.

It was fitting that Vancouver should have been chosen to host this conference, since British Columbia has the highest rate per capita of HIV-infected persons in Canada. In addition, this province has very progressive treatment policies. It has provided Can$7.5 million towards AIDS prevention, education, support and needle exchange services in 1996/7 (excluding care and treatment costs), an increase of more than $7 million on the $485 000 spent in 1991/2. It has committed $4 million to fund the protease inhibitors under the Pharmacare programme, and was the first province in Canada to fund what are being recognized as breakthrough drugs in the treatment of HIV/AIDS. Furthermore, British Columbia has increased the involvement of the AIDS community in shaping government's response to the issues of AIDS prevention, education and support services through the Provincial AIDS Strategy, launched two years ago.

Because of the venue of the conference and the gap since the last International Conferences in North America, it was hardly surprising that about 40% of the participants in the scientific programme came from North America. However, casual observation of the flow of people between the different conference sites revealed the truly international nature of the event, more marked than in previous years, with more than token representation from central and eastern Europe, the countries of the former USSR and the developing countries of south and south-east Asia. Official statistics indicated that there were more representatives from either India or Uganda than there were from Germany or Japan.

With the meeting being held at the height of the tourist season, as demonstrated by the impressive sight of cruise ships docking on either side of the Convention Centre and the occasional silencing of all discussion by the ships' sirens, accommodation was at a premium. Only some 60% of the 9000 rooms allocated for the conference were actually in the city of Vancouver, the rest being spread throughout the suburbs and university campuses and even as far away as Semiahmoo, across the US border, and the resort of Whistler in the Rockies, a good 3-hour bus journey away. The city's tourist agency calculated that the conference would generate some Can$31 million in revenue: $14.4 million on accommodation, $1.3 million on private transport; $0.6

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CAB INTERNATIONAL

million on public transport, $7.6 million in restaurants, $4.9 million on shopping and other spending, $1.0 million on hospitality suites, and $1.4 million on recreation and entertainment. (Some questioned these figures on the grounds that the conference was "serious", with delegates spending their time attending sessions rather than contributing to the local economy, whereas others pointed to the captive nature of the event with delegates staying within the city rather than spreading out to the resorts. In any case, it all points to the fact that the conferences are big business besides their scientific content.)

The conference was the biggest that the city of Vancouver had ever hosted with more than 15 000 delegates, including more than 1000 media representatives. The main convention centre can cope with 8000 delegates but once the city had been chosen it became evident that this capacity would be insufficient. As a consequence the meeting was spread over 3 sites, with delegates being bussed between them. The result was initially chaotic, with people dashing from site to site. The trade exhibition was effectively deserted half each day once delegates departed for the other venues. The pressure of people was too great for some rooms, with overflow capacity often inadequate. (Several delegates complained at having paid large sums of money to travel and register only to be denied access to key speakers.) The media centre was cramped and singularly short on PCs; clearly laptops rule in North America and it was assumed that everybody would be so equipped. On the positive side the programme, although dense and long, allowed some time for assimilation of data and perusal of posters. Time keeping by speakers was generally good. The message centre was hi-tech, with voice recording capabilities and computerized access. An army of volunteer helpers was on hand to guide lost delegates (even when they did not know the answers they at least smiled helpfully). The pharmaceutical company Merck Sharpe Dohme provided the abstracts on CD-ROM and, when they ran out, floppy disks (which need Microsoft Windows 3.0 and patience: each search takes 90 seconds or more).

The budget for the event was Can $14 million but, unlike previous conferences, this one was self-financing in that it was not backed by any one institution or government; it was organized by the XI International Conference on AIDS Society, a not-for-profit, charitable body set up by four local Canadian researchers who played key roles in the organization and execution of the meeting: Drs Michael L Rekart, Martin T Schechter, Michael O'Shaughnessy and Julio S G Montaner. Funding was raised through corporate sponsorship, grants from foundations and donations from a variety of governments and institutions. Some 60% of revenues were expected to be generated from delegates fees. To counter the customary objections to the high costs for people from developing countries and to ensure at least some representation from the non-industrialised world, the organizers made especial efforts to secure funding for them. Health Canada donated 1000 free registrations and the Canadian International Development Agency (CIDA) contributed $600 000. Other donors included the US Public Health Service, the Japanese AIDS Prevention Foundation, the European Commission, the Overseas Development Administration in the UK and the pharmaceutical industry. Dr Rekart expressed the organizers' "profound disappointment" that not one of the major international aid agencies (e.g. the UN agencies such as the World Bank) contributed anything to the Scholarship Programme; "for every seven foundations and international development agencies that we approached for funding we received approval from one". The reason appears to be "donor fatigue". Despite this set back they raised some $2.5 million in contributions, special air fares and cheap accommodation from 29 agencies (including one publisher: Rapid Science Publishers who publish *AIDS*) and pharmaceutical companies. This allowed 1076 people living with HIV, front-line workers or people from the developing world to be awarded full or partial scholarships to attend (547 from the developed world and 529 from the developing world); these included 218 from Africa, 135 from Asia, 133 from Latin America and 17 from Oceania. Some 490 of the recipients identified themselves as infected with HIV. To help the selection of recipients of scholarships to attend the meeting, the 3367 applicants were asked how they would apply what they learned.

Conscious efforts were made in the preparation to learn from and improve on previous meetings. Besides the commitment to the involvement of developing countries the organizers heavily involved the community, with all the conference's advisory committees containing at least one community participant. Local groups such as the Pacific AIDS Resource Centre ran education programmes for several thousand local workers in airports, hotels, transport, the police and other services. Public Fora provided opportunities for the developments reported at the conference to be relayed to the general public. Committees (which with hindsight the organizers admitted may have been too numerous) were gender and geographically balanced. The traditional grouping of sessions into 4 tracks, basic science, clinical science, epidemiology and public health, and social science—research, policy and action, was retained, but within these tracks differing views of subjects were presented in formalized debate structure in the plenary sessions. The tracks were augmented with three "pathways" that reflected horizontal themes that cut across the four vertical tracks. These themes gave special emphasis to living with HIV, development and HIV, and women and HIV. The programme also included meet-the-expert sessions and distinguished-speaker sessions. Perhaps the most innovative addition was a series of practical skills-building conferences held in parallel. These covered a wide variety of subjects such as use of e-mail, coping with burnout, nutrition for people with HIV/AIDS, proposal writing, and HIV resource centre operations. Outside the main conference there were 63 satellite sessions.

Some 5600 abstracts were accepted for the conference, about two thirds for display as posters. Besides the poster displays there were poster discussions, poster symposia, and roundtable sessions. A difference from previous meetings was that the abstracts were selected by a blinded review process. Authors' names and affiliations were removed from the abstracts before they were submitted to an international panel of some 800 people for selection, resulting in what the programme coordinator, Dr O'Shaughnessy described as an "abstract-driven conference". The main issues to emerge were, for treatment, the question of early introduction of therapy, cost and accessibility, for prevention the fact that there are success stories, and for the social sciences the nature of the obstacles to prevention and how to overcome them. (Despite this careful approach to content it is strange that

issues around children should have been so little touched on; although "adolescents/youth" was the fourth most frequently assigned keyword by abstract presenters, "paediatric" or "children" were not among the first 17 terms.) The panel were also asked to score the abstracts and the authors of the two highest scoring abstracts in each track submitted by researchers 35 years old or younger were awarded a grant of $2000 each towards their work.

Whether it was the sunshine (throughout the conference; locals said that we had enjoyed all their summer condensed into one week) and the setting or the biomedical developments of the past few months, the mood was rare for the AIDS conferences: one of optimism, a change from what Peter Piot of UNAIDS described as the perception of a collective depression two years ago in Yokohama. "We know what works" in prevention, we were told, and examples were given of success stories. The word "cure" hovered in the air. Despite the best attempts of scientists and most reporters to emphasize the preliminary nature of the results of small trials of combination therapy, the message from the conference seems to have had more hope than perhaps was evident after any of the preceding 10 conferences. Despite the justifiable caution it did seem right that some scientists quoted Churchill's wartime verdict: "it is not the beginning of the end but the end of the beginning"—at least in terms of the prospects for treatment and then for treatment of people in the industrialized world. Even the protests were more restrained (in sharp contrast to the Montreal meeting in 1989 when the tension was electric as armed Mounties patrolled the podium that had been taken over by protesters while luminaries such as the President of Zambia waited helplessly behind stage), although it apparently took some persuading of the local police that demonstrations and protests were part of the event. The organizers were prepared for "zaps" of pharmaceutical company stands and had staff ready to help tidy and clean up after the protesters had left.

Nevertheless, this wave of optimism about the advances in therapy obscured the fact that the epidemics of HIV and AIDS continue to surge on, although with surprising variations in pace which are hard to explain—for example the rate of spread of HIV in the Philippines, Zaïre and Indonesia is lower than expected whereas that in South Africa, Botswana and Cambodia has been disturbingly rapid. Part of the reason lies in the inadequacy of behavioural and social data. The optimistic mood also tended to obscure the fact that even where the rates of prevalence are stabilizing they have reached very high levels. The main burden in the worst affected area so far, sub-Saharan Africa, is yet to come. Access to care is still inequitable; as Josef Decosas, an international public health consultant emphasized in his plenary talk, "if the cure for AIDS was a clean glass of water, most people in the world would not have access to treatment". The lessons of AIDS history have not been learnt. Preventive efforts are coming too late and even strategies that have long proved to be successful such as needle-exchange schemes are still far from universal—the USA still has conservative objections to their principle and legal impediments to their implementation. Progress towards effective vaccines is painfully slow. Discrimination and stigmatization remain. The challenges of poverty, power, gender issues, access to care, and marginalization are as daunting as ever. Children seemed to have disappeared from the agenda, apart from a plenary session on the impact of HIV on families and children. The speech by Katherine Nyirenda, an HIV-positive mother from Zambia reduced many participants to tears. Her thanks for the support for bringing her to Canada included the bitter (but true) comment that the cost of her ticket would feed her children until they became adults.

The opening ceremony was rich in passion, emotion and culture. A surprised audience was greeted by a mature woman dressed elegantly in white. Doreen Millman from Vancouver drew thunderous applause with her opening remarks: "you're wondering how someone like me, a 63-year-old grandmother, got infected. The answer is simple. ... It just doesn't matter." There were welcomes and prayers from indigenous peoples and presentations of the global and human impacts of HIV. The appearance of Canada's Health Minister David Dingwall was the cue for protests; some delegates turned their backs and covered their ears, others blew whistles and shouted, all protesting at the absence of the Prime Minister and the government's failure to renew its AIDS strategy. Eric Sawyer of ACT-UP and living with HIV/AIDS maintained the level of passion with high rhetorical sound bites, particularly denunciations of government and condemnation of "AIDS profiteers". He called on pharmaceutical companies to lower the prices of drugs and to introduce a two-tier pricing system, one that would allow reasonable profits in the developed world and another that would make medication available at cost in the poorest countries of the world. Positively, he called for a partnership between people with HIV/AIDS, drug companies, the broader business community and governments to make treatment and prophylaxis available for tuberculosis, *Pneumocystis carinii* pneumonia, and diarrhoeal diseases—the major causes of mortality in AIDS. Drugs for these conditions are cheap. He concluded with a call for global access to health care. This echoed the theme of Dr Peter Piot, Executive Director of the joint UNAIDS programme, who said simply that "it is unacceptable that people living with AIDS should have to live without the essential drugs they need". He insisted that the global AIDS research agenda needed to be turned upside down. "Ignoring the research needs of 90% of the epidemic is not just unethical. It is irrational." He closed by quoting the French revolutionary Danton: "*il nous faut de l'audace, encore de l'audace, toujours l'audace*" (audacity, more audacity, always audacity).

Basic Science

Overview

Deborah L Birx of the Walter Reed Army Institute of Research in the USA gave the first of four summary reports of each track late on the closing day of the conference. The chair of this rapporteur session introduced it by saying that the need was now to translate the potential energy of all that we had heard and learnt into kinetic energy, in other words to translate the scientific and clinical knowledge into practical applications in the community. Birx identified five key areas of development in basic science: new tools and techniques (in virology, immunology and diagnosis),

pathogenesis, therapy, vaccine research and molecular epidemiology (international genotyping, or the international distribution of genotypes).

New tools and techniques

Scott Hammer of Harvard Medical School had opened the conference with a plenary (Mo 01) outlining the advances in the monitoring of viral load and antiretroviral therapy. The development of assays to measure the amount of viral RNA in plasma (viral load) has provided tools for the improvement of our understanding of pathogenesis (such as the compartmentalization of HIV), the monitoring of new treatments and the determination of the risk of disease progression. Julio Montaner of the Canadian HIV Trials network told a satellite symposium that viral load had replaced CD4⁺ cell count as a predictive marker of clinical outcome; CD4⁺ cell counts measure damage already done whereas viral load predicts damage to come.

The ability to obtain full-length HIV DNA from primary virus cultures has been critical to the determination of genomic sequences and so the determination of the genetic relationships between the various subtypes of HIV-1 and the common features of recombinant forms of HIV (reviewed by Francine McCutchan *et al* Mo 02). Whereas subtypes A–D are largely distinguishable in their genes, subtypes E and G are recombinant. In the absence of full genome sequences of subtypes F, H, I and J it remains possible that they too are recombinants. Recombinant forms of HIV have been found worldwide (see below).

Advances in immunology include the recognition of the role of chemokines and their receptors [cf items 359 and 531] and the role of CD8⁺ cell suppressor factors (CAF). Dr Robert Gallo, now of the Medical Biotechnology Center of the University of Maryland, Baltimore, described the cystine–cystine chemokines which specifically inhibit HIV. They have been detected at high concentration in people who have been frequently exposed to HIV but remain uninfected. They appear to act by directly blocking entry of HIV into CD4⁺ cells via the V3 loop of the viral envelope glycoprotein. The cell receptor binds to the chemokine as well as to the virus's V3 loop; binding of the chemokine thus blocks the receptor and prevents the virus from binding and entering the cell. He suggested that the presence of these chemokines may explain the long-term non-progression of HIV infection seen in some people as well as the apparent resistance to infection by HIV seen in others. This understanding of the second receptor for HIV and of these suppressor factors may lead to potential new therapies. But in this regard Gallo stressed that we have a moral obligation not only to make HIV disease manageable but also to make it affordable.

Jay Levy's group in San Francisco showed that CD8⁺ cells from lymphoid tissue of HIV-infected people suppress HIV replication, consistent with the antiviral activity of such cells from peripheral blood mononuclear cells (D J Blackbourn *et al* ThA 102). CD8⁺ cells expressing CD28 appear to be primarily involved in the suppression of HIV replication and the engagement of the CD28 molecule on CD8⁺ cells may enhance this antiviral response (E Barker *et al* (ThA 101) while work at the National Institutes of Health indicates that the modulation of HIV replication in CD4⁺ cells is controlled by a multifactorial process with many inhibitory and enhancing factors (D Weissman *et al* ThA100). The loss of ability of CD8⁺ cells to contain HIV appears to be related to the loss of CD28 molecules (D Lewis *et al* TuA 381). Other American work showed that stimulation of the CD28 receptor lead to polyclonal activation of CD4⁺ cells and rendered CD4⁺ cells from uninfected donors resistant to HIV-1 infection (B L Levine *et al* WeA 405). Expansion of CD3/CD28 expression may be linked with immune restoration (see e.g. M Carlesimo *et al*, WeA 3074), J B Margolick *et al* WeA 404). The non-cytolytic activity of CD8⁺ cells involves the secreted cell antiviral factor (CAF) and this appears to act, at least in part, by interrupting HIV transcription through genetic elements within the long terminal repeat of the viral genome (A Sato *et al*, ThA 105).

Other technological developments include the creation of a chimeric virus derived from SIV and HIV-1 that infects rhesus monkeys and causes AIDS (C Cheng-Mayer *et al* WeA 401), opening the way to an animal model for HIV/AIDS. Researchers have developed new, simpler and faster methods for counting CD4⁺ cells, making the technology available to developing countries. Retroviral vectors are now being used to carry genetic payloads and infection of stem cells will allow new gene therapies. Some of these advances will have not only direct application in the treatment of HIV disease but also benefit in other diseases and for medical and immunological research generally.

In terms of diagnosis the use of dried blood spots and the development of new enzyme-linked immunosorbent assays are leading to new testing algorithms that will reduce costs and be used internationally with no loss of accuracy. Home testing kits with telephone counselling were reported to be a safe and effective alternative to conventional testing and face-to-face counselling (A P Frank *et al* MoB 1183). New polymerase chain reaction assays for HIV DNA, not only from subtype B, are being developed (see e.g. T Gleeson *et al* MoA 160 and C D Christopherson *et al* MoA 161).

We still need very cost effective measurements of viral burden, for all subtypes of HIV, not just subtype B. Further we need to be able to quantify the cell-mediated response to HIV-1, again for all subtypes. We need a better understanding of the relationship between helper T cells, cytotoxic T cells and suppressor factors in the immune control system. And the recent data on chemokine receptors reveals our ignorance of their normal immunological function. Such knowledge about the chemokine receptors, in particular CKR5 and fusin, will be important for our understanding of pathogenesis and treatment, for we cannot consider interfering with their function if we do not know what that is.

Pathogenesis

In a debate on pathogenesis between David Ho and Giuseppe Pantaleo, Ho argued that viral factors are the primary determinants, with viral load being the direct predictor of disease progression. While host factors play a role the virus is the overriding engine that drives pathogenesis. Pantaleo argued that host factors influence bacterial and viral infections by modulating the immune response, in other words that it depends on the individual's genetic make-up. Pantaleo observed remarkable differences in an individual's disease course depending on the type of immune response during primary infection.

The degree of viraemia during primary infection was not indicative of pathogenesis; only later in infection did it become so. Qualitative differences in immune response rather than viraemia during the first few months of infection determine the clinical outcome of disease.

The chemokine receptors CKR5 and fusin have been associated with different viral phenotypes, CKR5 with the non-syncytium-inducing strains (NSI) of HIV-1 and fusin with the syncytium-inducing (SI) strains. These two phenotypes have been shown to have different abilities to infect cells. B M Polliotti *et al* (TuA 145) found that macrophage-tropic NSI strains of HIV-1 were able to infected human placental tissue while a lymphocytotropic SI strain could not. A French group (V Schneider *et al* TuA 2061) reported that amino acids 306 and 320 in the gp120 envelope glycoprotein constituted critical determinants for the syncytium-inducing phenotype. A Japanese study ((I Sestuko *et al* TuB 2238) found that SI variants emerged soon before the $CD4^+$ cell count began to decline; SI strains may be exposed to strong immune pressure before $CD4^+$ cell decline. The dominant clone of the NSI strain persisted longer suggesting that the NSI genotype is the escape mutant throughout the clinical course. The transition from NSI to SI phenotype has implications for the ecological niches of the virus.

Viruses isolated from two patients with AIDS dementia showed different properties. K Brengel-Pesce *et al* (WeB 3283) found that all subtype B viruses isolated from the cerebrospinal fluid had a NSI phenotype whereas the subtype D virus had an SI phenotype. The authors suggest that the pathogenesis of subtype D infection may differ from that caused by subtype B.

Several presentations demonstrated the enhancement of the infectivity of HIV-1 by normal components of human plasma. This topic needs further research in order to identify whether components of plasma enhance viral infectivity generally.

Since the Yokohama meeting in 1994 much more has been learnt about viral dynamics, reviewed here by John Coffin (Th 18). Research indicates that more than 10^9 new viruses are produced in an infected person each day, with infected cells having a half-life of about 1.6 days indicating something like 180 new generations a year, and thus considerable chances for the evolution of mutations. The large pool of viral mutants and variants will enhance the viral flux and fitness. We have also advanced our understanding of the variety of cell types that HIV can infect, such as megakaryocytes (affecting their ability to differentiate) and mesangial cells. This latter phenomenon may explain some of the renal dysfunction seen in HIV-infected patients. Both specific and non-specific mechanisms for pathogenesis are being advanced, involving viral load, CD4 and CD8 and other immunological functions and the impact of therapeutic regimens on the balances between them. Further understanding of the complex mechanisms could lead to new potential therapies.

While the enthusiasm for potential biological and immunological therapies directed at viral entry through a second receptor and suppressor factors is understandable, there is obvious concern about the effect of antiretroviral therapies on the immune function. For example, will new drugs exacerbate the suppression of a damaged immune system?

Research has now clearly shown that HIV directly suppresses the immune system. Many of the viral proteins themselves are immunosuppressive, including gp120, gp160 and p24. In acute infection $CD4^+$ cells are little help. Even non-infectious defective HIV particles are immunosuppressive and potentially cytotoxic. Patients who have early clonal depletions of cytotoxic T lymphocytes rather than a vigorous broad immune response fare badly, with specific loss of $CD4^+$ cell memory and diminished repertoire. In addition there is enhanced $CD4^+$ deppletion trhough activation and apoptosis. Thus HIV acts specifically and unspecifically and these immunopathogenetic mechanisms enhance the development of opportunistic infections as well as hinder the immune defences against HIV. Although these effects may appear daunting, they illustrate the extent of the advnace in our understanding.

Treatment and the preclinical development of drugs and immunotherapies

Reviewing developments in therapy in Track A Birx referred to the confirmation of survival benefit of treatment given to patients with $CD4^+$ cell counts of 200–500/µl, the dramatic reduction in maternal transmission when zidovudine is given in pregnancy and during birth, the value of treatment during the seroconverting window period and the value of combination therapy. M A Wainberg *et al* (MoA 380) reported that lamivudine (3TC) may increase the fidelity of HIV reverse transcriptase and recommended the inclusion of the drug in combination therapies for that reason. New classes of protease inhibitors were reported and this should soon lead to increased availability of such therapies. These compounds included dihydropyrones (H I Skulnick *et al*, MoA 1081, R A Chrusciel *et al* MoA 1085, T J Kakuk *et al*, MoA 1086, F J Schwende *et al*, MoA 1087, S Thaisrivongs *et al* TuA 261, S M Poppe *et al* ThA 153) and non-peptidic cyclic sulphones (C U Kim *et al* MoA 1075). Other inhibitors are being discovered and investigated, for example integrase inhibitors (equisetin; D Hazuda *et al* MoA 1020), inhibitors of Tat and Rev (aminoglycoside analogues; W Brown *et al* MoA 1052) and inhibitors of fusion (a 36-mer synthetic peptide analogous to part of the gp41 membrane; P L Black *et al* TuA 263). Resistance is clearly a major issue for new as well as established classes of drugs.

New delivery systems hold promise. P Harvie *et al* (ThA 155) reported that liposomes greatly improved the delivery of antiviral agents into the lymphoid tissues of rats. Polyhexylcyanoacrylate nanoparticles were also reported to improve the cellular uptake of antiviral compounds (A Bender *et al* MoA 1056).

Several approaches to gene therapy are reported. The *antitat* gene protected both T cells and stem cells and was active against SIV, leading J Lisziewicz *et al* (MoA 1046) to suggest that the SIV–monkey model could be useful for evaluation of gene therapy. Ribozymes were shown to increase viral killing in the macaque model. A Japanese group suggested the use of HIV vectors for gene therapy (M Matsukura *et al* MoA 1043) while an Italian group reported that a non-producing HIV strain blocked the HIV life cycle in both acutely and chronically infected cells (M Federico *et al* MoA 1042); both these approaches may be difficult to "sell" to the public.

Besides the pharmacological approach to treatment there are biological and immunological approaches. Improved understanding of chemokine receptors could lead to the development of their inhibitors and similarly with cellular activation factors. Immunological efforts will include the *ex vivo* expansion of both T cells and effector CD8 cells and the expansion of CD3/CD28.

Birx commented that in terms of combination antiviral therapy the approach towards the optimum combinations is following the oncology model, with national and international teams co-operating in large trials. Maximum antiviral effect may come from the combination of chemical, biological and immunological treatments

Results of attempts to restore immune function were reported. Clinical trials of CD3/CD28 expansion are due soon while other attempts focus on interleukin-2 and interleukin-15, which is a better candidate for bolstering immune responses and $CD4^+$ cell counts (P R Skolnik *et al* MoA 141).

Treatments that modify the immune response or enhance the body's immune system (immunotherapy) are not well developed because knowledge on the immune responses to HIV is still limited. Bob Gallo, Anthony Fauci and Jay Levy discussed the role of certain cell factors, known as chemokine associated factors or $CD8^+$-cell antiviral factors (CAF) (see also p 24 above). These factors, like "RANTES" or "MIP", gained wide attention when first described last year and were thought to inhibit HIV replication in the body; an Italian–American team suggests that they act through a step other than the initiation of transcription (A Garzino-Demo *et al* TuA 394). Results from further experiments now indicate that these factors alone are not sufficiently effective to inhibit HIV (A Rubbert *et al* TuA391). Other factors like CD28 may have a co-stimulatory antiviral effect (D C St Louis *et al* TuA 271).

Immunotherapeutical research has not yet led to a feasible approach in clinical practice. Even long known substances such as Imreg 1 and 2 which may enhance cell-mediated immunity (A A Gottlieb *et al* TuA 270) are far from being a breakthrough in immunotherapy.

Vaccines

Progress has been painfully slow on the vaccine front. We are still trying to understand and define the correlates of cellular protection and the role of cytotoxic lymphocytes is still controversial. Jonathan Heeney and colleagues in Europe (MoA 404) reported that neither a Th type 1 versus Th type 2 response nor absence of cytotoxic T lymphocyte responses correlated with success or failure of a vaccine candidate to elicit protective immunity in non-human primates. Conversely induction of cytotoxic T cells with a non-pathogenic strain of HIV-2 was associated with protection and lack of transmission. Jay Levy has shown again that $CD8^+$ cells are critical and it seems probable that $CD8^+$ cells mediate both specific lysis and non-lytic suppression.

Interest in humoral immunity, specifically neutralization, has been rekindled. Animal studies have shown protection associated with neutralization of homologous virus and many groups are mapping antibodies to identify the conformational requirements of both antibodies and the V1 and V2 loops. S Zoller-Pazner *et al* (MoA 406) reported that candidate vaccines did neutralize most primary clade B virus strains and developed a new resting cell assay. This assay should allow closer scrutiny of the efficacy of vaccine candidates and a better understanding of humoral immunity. Mapping of the HIV envelope region in the area of the second receptor may help identify a consensus epitope that will generate protective antibodies to all classes of HIV-1.

Two initiatives were announced at the conference. The first was the International AIDS Vaccine Initiative [IAVI, see issue 4, pp1-3 for details]. Seth Berkley of the Rockefeller Foundation described the current level of support for vaccine development at the National Institutes of Health (NIH) in the USA, 8% of its AIDS budget, "scandalous". IAVI has raised $5 million for its first year but is aiming to raise $50 million over the next three years. The other initiative was a restructured, redirected research programme on vaccines by the Office of AIDS Research at the NIH. Dr William Paul, the OAR's director, promised to implement fully the recommendations of the recent comprehensive review of the NIH's AIDS research programme. These revolved around a larger, fully integrated vaccine research programme directed by a leading non-government scientist.

Therapeutic vaccines

Therapeutic vaccines are closely related to immunotherapy: by challenging the immune system with a certain substance, a favourable reaction against HIV is expected to be triggered. A substance under study for more than five years has been rgp160, a genetically engineering envelope glycoprotein from HIV. Several drug companies, including the Austria-based Immuno and America's MicroGeneSys, have sponsored trials. Results of MicroGeneSys' rgp160 (C M Tsoukas *et al* TuA 274, D Birx *et al* TuA 275) indicate that the use of rgp160 in HIV-infected persons is safe. Disease progression was no faster in these trial participants, and adverse effects are mostly limited to the injection site. On the other hand, there was no convincing effect observed after several months of treatment with repeated injections of rgp160. For example, the number of $CD4^+$ cells did not increase (there was even a decline similar to the unvaccinated control group) and it was felt by many conference delegates that the Vancouver presentations marked the end of rgp160 research.

The end might also have come for anti-CD4 idiotype vaccination which was tested in a clinical phase-II trial since no convincing data for the efficacy of IOT4a could be presented (G C Sutor *et al* WeB 294).

Preventive vaccines

Since HIV was first described, researchers have been working to develop a preventive vaccine. It is widely felt that a preventive vaccine, once available, will make a major contribution to the fight against HIV/AIDS. A vaccine has "highest priority" (J Y Killen *et al* ThA 283) and is "urgently needed", UNAIDS representative Saladin Osmanov said (cf WeC 463).

New results on different approaches of vaccine research were presented. A directly injected plasmid (a DNA molecule) is a candidate for a new type of vaccine against HIV. For example, J D Boyer *et al* demonstrated that an

envelope DNA-based vaccine induced protection against HIV-1 infection in chimpanzees. Japanese groups (e.g. J Fukushima *et al* MoA 150) induced neutralizing antibodies in Japanese macaques by injecting genetic material (the expression plasmids for Gag, Env and Rev proteins), and reported that the combination of DNA vaccines with peptides could induce high levels of immunity (K Hamajima *et al* MoA 151). In a first human trial (R R MacGregor *et al* WeB 293), 13 asymptomatic HIV-infected persons were injected with an HIV DNA plasmid vaccine; no local or systemic side effects were observed, but it is still too early for an evaluation of the efficacy of this new approach.

Virus-like particles (VLP) provide another new approach to vaccine development in particular because a non-replicating system is used. G Gaetano *et al* (TuA 2064), F L Yao *et al* (TuA 2098) and Y Shao *et al* (PubA 1024) reported on the development of non-infectious HIV-1 particles which are currently undergoing laboratory testing.

Subunit vaccines, consisting of envelope glycoprotein (gp120), appear to be safe (D P Francis *et al* MoA 283), but it is unclear whether rgp120 may prevent HIV-1 infections in humans (P W Berman *et al* MoA 285). Ten of 507 adults participating in phase I and II vaccine trials of MN-rgp120 have become infected with HIV-1. In the meantime, phase II clinical trials with this substance are under preparation in Thailand (S Migasena *et al* WeC 460). Even if MN-rgp120 seems to be highly immunogenic and induced neutralizing antibodies, its protective potential remains to be defined.

Another gp120-based product has been tested in phase I and II trials in Thailand and will now possibly enter larger clinical trials (A M Duliège *et al* WeB 3376). Chiron's Biocine product has been under development since 1984 and was the first recombinant vaccine for a viral disease. Ms Duliège called it a "misconception by the public" that a vaccine has to be very effective to be worthwhile the research—thus opening the door for the further investigation of a vaccine which might have an efficacy of only 50% or 60%. The same argument applies to the use of current cholera vaccines. A phase II trial might "in the best circumstances" start in 1998, "if it ever starts". Biocine Corporation and Genentech are also developing a rgp120 vaccine (M J McElrath *et al* MoA 284).

Vaccine research appears likely to enter a new phase of clinical trials in the near future. So-called empiricists who prefer the trial-and-error method seem to determine the field. The National Institute of Allergy and Infectious Diseases in the USA has implemented a strategic plan in which empiric development of vaccines plays a major role and is listed first (J Y Killen *et al* ThA 283). Basic researchers and theorists who look for a perfect model before entering a new phase of clinical research that would involve large numbers of human volunteers were hardly heard at Vancouver. Oral presentations and extensive documentation of these sessions in the official conference newsletter suggested that time has come to move on. This move will be supported by the International AIDS Vaccine Initiative (IAVI). Apart from the fact that vaccine research is rather slow, no critical comment on vaccine development could be detected in the IAVI's press folder or in Margaret Johnston's presentation (ThA 280).

From a pharmaceutical company's perspective, vaccine research requires partnership, collaboration, and commitment to a mutually agreed development plan, said Ann-Marie Duliège. Pharmaceutical companies need a clear indication of what product is wanted before they can be expected to commit themselves to what is likely to be extremely costly research in a very complicated field. Since 1992, the World Health Organization and now UNAIDS have been working with national authorities and scientists of Brazil, Thailand, and Uganda to develop and implement comprehensive plans for HIV vaccine research, development and evaluation, and to strengthen field sites for vaccine trials. At Vancouver, speakers from several developing countries confined themselves to further vaccine research (e.g., K E Mbidde, Uganda ThA 285, who said that developing countries "should do all they can to remove barriers likely to deter" research efforts).

Several studies investigated the willingness of community groups such as gay men or drug users to volunteer in preventive-vaccine trials. This willingness seems to be high in Brazil (81% of participants, R F Lago *et al* PubC 1119; 50.7%, J J Fonseca *et al* WeD 3748), but also high among injecting drug users in the USA (78%; P Gainst *et al* MoC 1590) and gay men (37% "definitely", 57% "probably" willing to participate; S Buchbinder *et al* MoC 1592). Fears about participating in a vaccine trial were discussed in a French study (A Giami *et al* MoC 1587)—fears of being treated as a guineapig as well as the fear of being infected by the vaccine.

Remarks on social, ethical, and behavioural issues in vaccine research were limited to one poster (A R Sheon MoC 1591). The Community Vaccine Network, initiated and organized by Brazilian AIDS organizations such as Grupo Pela and ABIA in association with the Brazilian Health Ministry, and joined by the French association Arcat-Sida, issued a document which stated some general principles concerning vaccine research. Unfortunately, this document remains unclear on major issues, such as community participation in study design. As in other clinical trials, community members should be allowed to contribute to the study design before it begins. A community advisory board should be installed, and members of the community should be on the data and safety monitoring board which is usually the decision-making committee. But, alas, as long as the community does not ask for such involvement, AIDS vaccine research will continue to be dominated by large pharmaceutical companies and some scientific institutes such as the Walter Reed Institute of the US army.

Many questions concerning vaccines remain yet to be solved. How effective will future vaccines be? Will they have a negative impact on prevention efforts in developing countries where they will be tested? How expensive will vaccines be, provided that they will ever be licensed for marketing? Will developing countries have access to these vaccines?

Saladin Osmanov of UNAIDS and representatives from drug companies avoided answering questions about availability of a vaccine in the country where it has been tested. A Greenberg (ThA 260) addressed this question, saying that vaccines that are tested in developing countries should be made available to the citizens of those nations should they be shown to be safe and effective. There was no agreed model on how the "World Vaccine" (UNAIDS terminology) will be distributed. For the time being, vaccine research leaves us with more questions than answers.

International genotypes of HIV-1

Studies on the genetic subtypes of HIV-1 and their distribution indicate that they have spread globally and that recombination is a good deal more common than hitherto supposed, and

gave basis to the "one world" part of the conference theme. A Finnish group (K Liitsola *et al* TuA 2058) reported finding 6 different subtypes (A, B—most commonly, C, D, F—rarest, and G) in Finland, the Baltic countries and Russia. Subtype F is spreading in Brazil (M G Morgado *et al* TuA 103), mixing with subtype B already there, while E continues to spread in Thailand and south-east Asia (P Auewarakul *et al* TuA 104). In South Africa the initial subtype B/homosexual epidemic has been overtaken by a heterosexual subtype C epidemic (C Williamson *et al* TuA 101); similarly in Israel the local population was predominantly infected with subtype B whereas the Ethiopian immigrants carried subtype C (U Dietrich *et al* TuA 105). In Germany a third of [a small number of tested] strains have been found to be other than B while the figure in New York is 15%. Subtype O has been discovered now in seven African countries plus France and Spain. Dual infections with group M and group O viruses have been detected. Overall, the picture reveals non-B viruses spreading into areas where previously subtype B dominated. In North America the viral pattern now emerging is a mixture of types B, D and E. This change in molecular epidemiology has clear implications for vaccine development (which so far has mostly concentrated on subtype B virus). Subtypes appear to have different properties, for example types E and C multiply differently in different cells and E infects Langerhans cells rather than peripheral blood mononuclear cells. There has been some speculation that HIV subtype E has the potential for rapid spread by heterosexual transmission by virtue of the fact that Langerhans' cells, which are present in the vaginal mucosa, have been shown in the laboratory to be easily infectable by this subtype. However, the introduction of non-B subtypes is not very recent. Such subtypes have been circulating for over 10 years in Belgium, which has long-standing ties with central Africa, yet there is no evidence of a fast heterosexual spread of HIV in that country. Care should therefore be exercised in using laboratory data to predict epidemiological patterns.

Recombination will increase the viral diversity and consequently the fitness of HIV-1 to infect and survive. Many reports described recombination in HIV-1. E and G are not strictly subtypes but recombinants with subtype A. There are specific breakpoints within the HIV-1 genome that enhance the formation of A/C, A/D, A/E, A/G and B/F mutants. Chimpanzees have been successfully superinfected with different strains (B and E) followed by recombination. Similar recombinations have been reported in humans. More research is needed to determine whether specific viral variants will flourish and amplify within different social networks of HIV transmission. This represents a major concern with possible dangers of increased transmission potential, increased virulence and increased adaptation as well as the implications for vaccine development.

Clinical Sciences

Among the 163 oral presentations and 1194 posters in this track, three related topics emerged as the dominant themes, with overlap over the previous track: viral load, protease inhibitors and antiretroviral combination therapy. Kevin De Cock of the London School of Hygiene and Tropical Medicine elegantly reviewed developments in his rapporteur session.

Whatever drugs are used to treat HIV infection they are unlikely to be of benefit without the means to measure their efficacy accurately. Considerable advances have been made in the monitoring of the level of virus in blood (viraemia), which was reflected in a session on viral load (B1, 336). Viral load is directly proportional to the number of T cells and the number of virions and people with low viral load have a better prognosis than those with a high load. Initial viral load could be determined, according to David Ho, by the size of the initial inoculum of HIV and the phenotype of the virus (long-term non-progressors have attenuated virus, e.g. with deletion of the *nef* gene) while host factors such as age at infection and lack of some receptors for HIV obviously also have a role. The combination of viral RNA measurements and $CD4^+$ cell counts is a very powerful prognostic tool and a regression tree with these parameters can be used to predict survival on an individual patient basis. This development holds the possibility not only of predicting survival but of fine-tuning antiviral therapy according to treatment response for greater efficacy.

Techniques to quantify plasma viral RNA include reverse transcriptase PCR, branched DNA assays and nucleic acid sequence-based amplification (NASBA). NASBA may show higher levels of HIV-1 RNA as well as a greater treatment effect, but sensitivity appears to be reduced in infections with subtypes other than B. The possibility of quantifying plasma RNA has led to the examination of viral load as a prognostic marker, as an outcome for evaluating antiretroviral drugs, and for tailoring therapy in individual patients (as Hammer outlined in his plenary, Mo 01).

Dr Ashley Haase of the University of Minnesota described a new visual assay for HIV RNA that detects and quantifies the virus in different tissues and cells, including follicular dendritic cells (which act as a non-productive reservoir for latent HIV) and productively infected mononuclear cells. The follicular dendritic cells were found to contain some 45 times more viral RNA than the mononuclear cells. The follicular dendritic cell pool is smaller in primary HIV infection than in later stages of HIV infection, and from these findings he argued the case for the early introduction of treatment.

John Mellors presented data on more than 1600 patients in the Multicenter AIDS Cohort Study (MACS) in the USA (WeB 410), which showed that viral load was a prognostic marker for the development of AIDS and for survival, independent of $CD4^+$ cell count. Measurement of plasma HIV RNA load was a better prognostic marker than $CD4^+$ cell counts, neopterin, thrush or fever. Compatible data were presented from Switzerland. Stratified by CD4 counts, survival was shortest in those patients with the highest levels of plasma HIV RNA. De Cock commented that such results underline the wisdom and vision of collecting large cohorts and sample groups for study.

Combination therapy

Speaking on combination therapy and noting the extensive list of drugs now available for treatment of HIV Professor Paul Volberding of San Francisco General Hospital agreed that "optimism is clearly the word of the day". From the data on the use of the combination of two nuceloside analogues and a protease inhibitor (he particularly referred to zidovudine plus lamivudine and indinavir) he assumed

Wellcome and Levi Strauss Inc but also Philip Morris Companies Inc, Molson Breweries and other drinks companies. Not everybody in business is convinced that AIDS concerns their organizations, although by now the importance of HIV/AIDS for the business sector in the developing world seems obvious. [For the main conference there were 22 corporate supporters, a fact that indicates that many do indeed remain to be convinced, especially given the large number of multinationals with interests in countries where prevalence rates are high.–*Eds*] The meeting addressed issues such as does HIV/AIDS need special attention? For developing countries the main impact has yet to come and so the answer will be affirmative but for the developed world the answer may be that it needs to be considered as one of a number of chronic diseases. The consensus regarding screening of employees is that it is not desirable. The response of a business to HIV/AIDS will depend on its size, and attention needs to be paid to the position of small firms on which the impact of HIV/AIDS illness and death will be disproportionate. Downsizing will also have to be considered in areas of high prevalence.

The question of the role of business in society was discussed, with the view being expressed that they need to do more than simply make a profit; they contribute to civil society and have responsibilities. This was neatly summed up in two quotes: "dead customers don't buy" and "we are all part of the community we live in and we all have a role to play". Generally companies are not responding, at least not in the way of giving HIV/AIDS issues priority in the company generally. That only happens when the senior management become aware and get involved. No magic solutions to improve this were forthcoming. Part of the reason is that there is the perception among management and policy makers that the gloomy scenarios of the 1980s have not been fulfilled; the continuing spread of the epidemic does not directly affect them or their business and the impact on marginalized communities appears to make it less relevant to the employment sector. [Short-term considerations also will play a role; few companies have units that project developments and social contexts over the next 25 years.] Governments still need to formulate a regulator framework in which business will work.

The meeting ended with a discussion of next steps and a declaration in the form of a mission statement for the global business response to AIDS: "to mobilize the resources of business locally, nationally and internationally in response to AIDS in a mutually beneficial effort to meet the needs of people affected by HIV and AIDS and society as a whole". Business needs to be involved because of: the economic imperative, workplace efficiency, the opportunity for effective prevention, corporate reputation, and marketing potential.

Conclusion

The hype and optimism were not without foundation. Genuine advances have been made since Yokohama two years ago in the basic and clinical sciences. New tools and techniques have been discovered and introduced. Assays can now detect and quantitate HIV RNA and viral load has replaced $CD4^+$ cell counts as a predictive marker. We understand more about viral dynamics and basic immunology although much remains to be discovered and elucidated. A new receptor and the identification of chemokines offer potential new approaches to therapy. Importantly, these advances will have implications beyond the confines of HIV; the benefits to science and medicine have not been measured but are real and should help answer some of the critics who point to the large sums being spent on AIDS research compared with that on other chronic conditions.

The ability to examine full-length genomes of HIV has benefitted clinicians, pharmacologists and epidemiologists. Research using this tool has shown the global dissemination and miscegenation of different subytpes of HIV. Resistance of HIV can be better tracked and the progress of clinical trials can be better monitored.

Progress in vaccine research has been slow and leapfrogged by the developments in chemotherapy, where combination therapy, in particular with two nuclesoide analogues and a protease inihibitor, is the standard of care. The cost implications have yet to be quantified fully and the extra costs will cause many ethical dilemmas as policy makers have to find ways of dividing limited funds for health care to public satisfaction. For developing countries the extreme limitation of funds for (and access to) health care must make most of the results presented seem like science fiction.

The story of long-term non-progressors has receded from attention. Some see the extended period of resistance to HIV disease progression as the end of a statistical spectrum while others point to the immunological role of chemokines as possibly containing or preventing infection. The encouraging news that some people do not get infected or progress to AIDS does not seem to offer more than hope and encouragement to a few.

Research into prevention through vaginal microbicides is gathering pace but there is still a long way to go. At least, also, it is recognized that the spread of HIV will not be halted by any simple technological fix. We need long-term efforts to bolster behavioural change and, in the current jargon, to increase empowerment at individual and community level, but with the caution that Western models and choices are not inappropriately forced into unreceptive contexts. There is an urgent need for good behavioural research into risk taking, sexual networks, reasons for behavioural change and ways of sustaining change, and patterns and determinants of preventive methods such as use of vaginal products. We need a better understanding of the impact of HIV/AIDS and its related conditions, better measures of development and socioeconomic impact, of individual and community coping strategies. Indeed we have been provoked to address the thorny questions of development—for whom, by whom, what are the long-term consequences, whose need is paramount: the people's, the state's or that of multinational corporations and banks? The external social parameters that define the continued spread of HIV and AIDS show little sign of improving: populations continue to increase, migrations for economic or political reasons continue, civil strife and conflicts show few signs of abating and the forecast for growing refugee populations is gloomy.

Sadly the evidence from the countries most lately affected by the epidemic, from Turkey to India and elsewhere in Asia, show that lessons have not been learned, experience that has been available has not been taken in. Prevention works; the message reverberated through the conference. Encouraging examples came from the alliance of military and civilian groups to increase awareness of HIV/AIDS in the military and to engage them in preventive interventions. Barriers can be broken and prejudices can be overcome, although conservative forces in countries that should be setting examples make this a long-drawn out and not always successful struggle (*vide* the obduracy with which the USA resists changing its immigration laws). But application of successful prevention interventions needs community involvement, commitment at all levels, including political will, and funding. We recognize that funding is tight in the present economic climate, but economists point to the fact that money does not disappear; it gets recycled. It is another challenge we face, to identify new sources of funding among those who are the beneficiaries of this recycling. The human tragedy, so eloquently exemplified by Katherine Nyirenda from Zambia, compels us to redouble our efforts to overcome the obstacles, whether organizational, social, political, economic, scientific or medical. Progress can and is being made, but the virus is a wily opponent and always seems to be one step ahead.

Peter Piot said that if he had to sum up the conference with three key points they would be: it was less West-orientated, with more discussion of developing countries; harm-reduction policies, other prevention initiatives and health education in developing countries have been successful; there is hope at last, hope which, even if it is like a see-saw, springs eternal.

Delegates left buoyed by a sense of optimism and a feeling that the corner has at last been turned in the fight against AIDS. The urgently needed International AIDS Vaccine Initiative was launched, which will give fresh impetus and direction to an area that was threatening to languish. Great strides have been made in the reduction of maternal transmission to as low as 8%, and studies are underway to see if it may be possible to reduce this further. Whether the new protease inhibitors (PIs) could help in the treatment of HIV-treated pregnant women and reduce maternal transmission is as yet unknown. Although it is too early to speak of a "cure", exciting progress has been made in combination therapy and hopes are pinned on results of clinical trials with PIs. However, the costs of some of these new treatments are daunting even to relatively well funded health care systems and will certainly be beyond the reach of most of those affected in developing countries, where 80% of the burden of new infection lies. To quote Robert Gallo, "We have a moral obligation not only to find therapies that make this disease manageable but to make [them] affordable". Sustained prevention efforts are now starting to pay off. Infection rates are stable or declining in some countries, including Thailand and Uganda, but not before, in the case of the latter, HIV has cut great swathes across the population. An analysis of the 1991 census held at both district and parish levels in Uganda revealed a profound effect of HIV on population distribution at parish and village levels in areas of high HIV prevalence. There were large population deficits, especially of adolescents and children aged between 0 and 4 years. Overall, stable or declining rates in regions may also mask increasing rates in certain countries or within population groups. The continuing high incidence rates among young gay men underscore just how little is understood about the behavioural determinants of risk- and decision-making strategies, or about risk-taking behaviour in primary relationships.

The conference brought forth a new challenge with the recognition that HIV subtypes have now spread to all continents, with all the implications that holds for prevention and control: "We are one world". HIV is continuing to spread into countries hitherto unaffected by the epidemic. The gap between care in the developed and developing world is widening, although the burden of the disease is in the south. As De Cock remarked, "We speak of one world but in reality we are worlds apart". Despite a better understanding of the spectrum of HIV-associated disease in developing countries, a minimum level of care that all HIV-infected persons should aspire to has still not been adequately defined. A policy for prophylaxis against opportunistic infections needs to be worked out, together with a concerted effort in the prevention and control of tuberculosis - a public health priority in its own right. There is a need for region-specific development, evaluation and implementation of guidelines for appropriated investigation and management of HIV based on the local spectrum of disease. Region-specific guidelines on prophylaxis and region-specific definitions of essential drugs are needed.

The clear need for efforts to be spurred on in the quest for effective vaginal microbicides was recognised with the announcement by Donna Shalala, US Secretary of Health and Human Services, that the National Institutes of Health and the Centers for Disease Control and Prevention plan to spend a cumulative total of more than $100 million on microbicide research over the next four years.

Calling for a renewal of energy, resources and commitment in the fight against AIDS, Martin Schechter said that the conference theme of "One world, one hope" must become a vision for the future: of worldwide prevention, treatment and cure, which will break the cycle of intolerance and misinformation. According to Peter Piot, it is the goal of UNAIDS to turn these hopes into reality. AIDS must be high on the political agenda for this to be possible. The G7 summit pledged to work with UNAIDS and the Paris AIDS Summit of 1994 was full of lofty resolutions, with participants signing a Declaration reaffirming the need for "*political leaders to make the fight against AIDS a priority*". However, as Eric Sawyer of ACT-UP remarked, "Government promises don't save lives: government action does". An analysis of the impact of the Paris AIDS Summit by ICASO (International Council of AIDS Service Organizations) revealed that 56% of the 42 countries represented are doing nothing to implement the Paris Declaration. It was also shown that the Declaration has made no difference in these countries with respect to preventing discrimination against people with HIV/AIDS nor has it resulted in any new measures to address the specific vulnerability of women to HIV/AIDS. Discrimination often occurs in settings (eg. with families and communities) that are not addressed or covered by legislation.

The need for solidarity in our response to AIDS was argued eloquently by several speakers who called for greater collaboration across all four Tracks of the conference as well as for greater cooperation and collaboration between scientists, pharmaceutical companies, governments, international organizations, NGOs, PWAs and activists. In a passionate speech,

Jonathan Mann argued that the public health response to the societal factors which constrain and influence behaviours and which create and enhance vulnerability to HIV has hitherto been fragmented. Richard Parker, of the Brazilian Interdisciplinary AIDS Association (ABIA) summed it up well: "By focusing our attention on social vulnerability, on empowerment and community mobilization in the face of AIDS as part of a broader movement for social change aimed at responding to inequality and injustice, we have begun to build a series of bridges that offer the opportunity to forge a truly global coalition. If we fail to....build upon this opportunity, the danger is that the very real differences that would seem to separate us - as seropositive and seronegative, as scientist and activist, as members of rich and poor societies, from developed to developing countries, and so on - will continue to broaden and be transformed into the divisions that are our greatest enemy against HIV and AIDS.....The true challenge implicit in the theme for the XI International Conference on AIDS [is] of working together to overcome the oppression, discrimination and violence that everywhere can be found to lie behind the apparent shape and structure of the epidemic. The challenge of building one world out of many by learning to respect our differences while at the same time moving beyond them in our common struggle. The challenge of drawing on the principles of solidarity as the basis of our work, and of understanding the fight against AIDS as part of a much broader project of social change."

The next international conference on AIDS is scheduled for Geneva in 1998, giving time for us to help shape the epidemic and the conference itself. Let us strive to be one step ahead of the virus by then.

Reports

The HIV Project in London has produced a report on Vancouver that gives a more discursive coverage of key issues in prevention. Also NAM's *AIDS Treatment Update* published a special conference issue (no 44).

Acknowledgement

This report has been compiled with the help of several colleagues and obviously is not meant to be encyclopaedic. Many excellent presentations will have been omitted for reasons of non-attendance through competing sessions, the impossibility of doing justice to the 5600 or so posters and abstracts and of course the constraints of space as well as time and energy and interest on behalf of the reader. Especial thanks go Hilary Richardson, Stephan Dressler, Simon Ellis and Alan Whiteside. I also thank Glaxo Wellcome for support in travel to Vancouver.

David W FitzSimons

3

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Marlou Bijlsma is a nutritionist. She has an MSc degree from Wageningen Agricultural University in the Netherlands (1987). She has worked in community programmes and with undernourished children in Mexico and Uganda and since July 1995 she has been attached to Mutare City Health Department.

Mutare City Health Department is currently expanding its community programmes. Nutrition is expected to play an important role, especially in Home Based Care and support for people with HIV/AIDS.

A nutrition course given in 1995 to members of the Family AIDS Support Organisation (FASO) was found to be very beneficial. Participants assisted in developing the course. The course was repeated for other members in 1996.

Some of the comments of the participants show their concern and their appreciation for the course:

" When I was diagnosed I thought it was the end."

" One day on the bus to Harare diarrhoea started and I even had to stop the bus. I realised I had to do something to control the diarrhoea."

" My mother had diarrhoea for four months. She had tried everything but nothing could help her. We followed the guidelines for diarrhoea and prepared rice porridge and vegetable soups. After two weeks the diarrhoea stopped."

" I am somebody who is living positively and taking these foods and preparing cough syrups and teas. But we want to share with relatives and friends. We want everyone to learn about living positively and about food and nutrition."

living positively

nutrition guide for people with HIV/AIDS

Marlou Bijlsma

MUTARE CITY HEALTH DEPARTMENT

living positively

nutrition guide for people with HIV/AIDS

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living positively

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To compose this booklet we have made extensive use of information published in other nutritional guides for people with HIV/AIDS:

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Sheila Murphy, **Healthy eating makes a difference, a food resource book for people living with HIV/AIDS** (Savoury Productions, Canada, revised edition 1995)

C. Wayne Callaway and Catharine Witney, **Surviving with AIDS, a comprehensive programme of nutrition co-therapy** (Little, Brown and Co., Boston, USA, 1991)

Ronald Watson (ed.), **Nutrition and AIDS** (CRC Press, Boca Raton, Florida, USA, 1994)

Simon Mills, **The essential book of herbal medicine** (Penguin books, London, England, 1991)

David Werner, **Where there is no doctor** (Macmillan, England, 1988)

The nutrition group of FASO chose the topics, tried out the guidelines and recommendations and selected the most useful ones.

The members of Mutare Community Home Based Care Forum submitted their comments. Especially we would like to thank Dr Diarmuid McClean (Mutare City Health Department), Luanne Epstein (Hope Productions, South Africa), Dr Roger Drew (Family AIDS Caring Trust Mutare), Ellen Ndimande (National AIDS Coordination Programme), Dr Sathi (Mutare City Health Department) and Gift Chatora (Provincial Training Officer Manicaland, Zimbabwe Red Cross) for their constructive comments on the draft of this booklet.

We thank the OAK Foundation Zimbabwe for making the production of this publication possible.

foreword

The HIV epidemic has taught us many things and has demanded that we revisit the way in which we live our lives. We are relearning the value of open-mindedness, trust, mutual support, unconditional love and the power of hope and positive living.

Although this booklet is aimed at people living with HIV/AIDS and their care givers, the messages and practical ideas are useful to anyone who is serious about positive living: what you eat makes a difference.

Try out the ideas and suggestions, they do work.

Diarmuid McClean
Medical Officer of Health

Introduction
Food and AIDS

Health care for people with HIV/AIDS has concentrated almost entirely on treating infections. Some studies however are showing that malnutrition has contributed to somewhere between 60 and 80 per cent of AIDS deaths (source Surviving with AIDS).

Food can not cure AIDS, nor does it treat the virus, but can certainly improve fitness and quality of life for people with HIV/AIDS. Eating enough and a balance of different food helps you to maintain your body weight and your muscles. The immune system is your body's protection mechanism against germs. Suitable food helps to maintain and improve the performance of the immune system.

Many of the symptoms of HIV/AIDS are treatable with appropriate nutrition. This makes sense when you consider that many of the infections that are associated with the disease affect food intake, digestion and absorption, while others influence body metabolism.

At the moment in Zimbabwe very little information is available on nutritional support for people with HIV/AIDS. Therefore we have compiled together whatever information we could source. The information has been discussed, tested and amended in cooperation with the Family AIDS Support Organization (FASO) in Mutare during nutrition courses in 1995 and 1996. As FASO members and City Health Department feel the nutritional support is extremely useful we would like to share this information and make it available to other people with HIV/AIDS and their care givers.

This booklet provides practical information on composing healthy diets in general (chapter 1). As people with HIV/AIDS have special food requirements to a certain extent, chapter 2 provides special recommendations. The remaining chapters contain sections about the most common problems that people with HIV/AIDS are facing. These include diarrhoea, weight loss, coughs, flu, mouth and skin sores. Some background information is provided about these symptoms in relation to the disease, as well as food related guidelines on how to cope with these situations. Where appropriate, recipes will be given at the end of each chapter.

Nutrition and AIDS is a new topic, which still needs much research. I would like to invite you to submit your suggestions and experiences in order to regularly update this booklet. Please give me feedback on what remedies you have found useful and on any remedies that have not been included in the book. For any questions, explanations or comments contact me at the Nutrition Unit of Mutare City Health Department.

Mutare, April 1996.

chapter 1

Making up a healthy diet

eating

Although everyone knows how to eat, we don't all know how to nourish ourselves. Deciding what, when and how much to eat is a complex process. It depends on a lot of different factors besides what is good for us. Things like availability of food, taste, appetite, how much money and time we have all influence the food we eat. Healthy eating is important to everyone.

When you are HIV positive, taking control of what you eat is even more important. Living with HIV means living with a weakened immune system. This makes you more likely to catch infections. Repeated infections lead to malnutrition. Because of this good nutrition is extremely important to maintain quality of life.

When you swallow your food it goes through your stomach into your intestines. In the process the food is broken down into nutrients which are absorbed into your system. Digestion of food starts in your mouth where you chew it and mix it with your saliva. In the stomach and first part of your intestines more digestive juices are added to help the breakdown of food and the absorption of nutrients. The nutrients are proteins, carbohydrates (starches), fat, vitamins, minerals and water. The body needs all these nutrients to function properly and stay healthy.

the nutrients in our food

To understand the principles of healthy food, it is important to learn about the nutrient composition of our food. We can divide the food we eat into three different food groups according to the most important nutrients it contains:

- food rich in carbohydrates or fat
- food rich in proteins
- food rich in vitamins and minerals

food rich in carbohydrates and fat

Grains, like maize, wheat, millet, sorghum, rice and barley, potato, sweet potato, cassava, yam and legumes (beans and peas) are rich in carbohydrates (starch) as are sugars. They provide the body with **energy**. Food rich in carbohydrates is usually easy to digest and cheap.

Oil, butter and margarine, fatty meat, chicken, fatty fish, peanut butter, nuts and seeds are rich in fats. Just like carbohydrates fats provide the body with **energy**, but fats can cause digestive problems.

food rich in proteins

Meat, chicken, liver, fish, milk, cheese, egg, beans, lentils, soya, groundnuts, peas, seeds and nuts are rich in proteins. Proteins build and repair the body. Proteins play an important role in the immune system. Proteins are made up of amino acids. Animal food products, like meat, milk and egg will provide a range of amino acids that is the same as what the human body needs. Vegetable protein sources like legumes (beans, lentils, peas etc.) do not provide the full range. Therefore they should be varied or combined with other (vegetable) protein sources. Good combinations are legumes with grains, milk or nuts.

food rich in vitamins and minerals

Vegetables like green leaves, cabbage, pumpkin, rape, tsunga, tomato, squash, green beans, peas, carrot, and fruits, like mango, orange, guava, banana, peach, pineapple, apple, paw-paw, plum, passion fruit, avocado pear and lemon provide the body with **vitamins and minerals**. There are at least 17 different vitamins and 14 different minerals. Each one has a special use in the body. The body cannot work properly if any one is missing. Each of the vegetables or fruits is rich only in a few vitamins or minerals, so it is important to eat a variety. Dark green and orange or red vegetables and fruits are best.

balance

Good nutrition includes a balance of proteins, fats, carbohydrates, vitamins and minerals. No single food contains every nutrient you need. A healthy meal is made up of at least one food item from each of the different food groups; so

one food item providing energy,
one food item providing proteins,
one food item providing vitamins and minerals

Healthy meals provide:		
energy and	*protein and*	*vitamins/minerals*
examples are:		
maize porridge	*milk*	*mango*
bread	*egg*	*orange juice*
sweet potato	*lacto*	*paw-paw*
sadza,	*beans*	*pumpkin*
rice	*peanut butter*	*green leaves*
sadza,	*meat*	*cabbage*

- Try to prepare each meal with the three components. If in one meal a part is missing, make sure you do not skip that item in your next meal.
- Try to vary the foods you eat. All foods have certain properties and certain nutrients they are rich in, while they may be short in others. Having different food to eat helps you to cover all needs.

Examples of incomplete meals:

	because	**to improve**
biscuits and coke	only energy	
bread and jam	only energy	add tea with milk and mash fresh fruits on bread
chips and chicken	only energy and protein	add fruit or vegetables

chapter 2

Food for people with HIV/AIDS

For people with HIV/AIDS it is important to keep as healthy as possible. Developing healthy eating habits is extremely important. The rules to making up healthy meals are explained in the previous chapter. As people with HIV/AIDS have specific needs some adaptations are useful.

weight

- Weigh yourself each week and keep records. You want to make sure you maintain weight. It is well possible that you think you are not loosing weight, while in fact you really are. If you are loosing some try to find out the reason. You have to take necessary steps in an early stage in order to get your normal weight again (see chapter 4 on weight gain).

energy

- With HIV/AIDS the body has an extra need for energy. **Fats** are an important energy source but they are difficult to digest and can cause or increase diarrhoea. Eat less oil and butter/margarine if you have diarrhoea. Increase the amount of **starchy** food to provide the necessary energy.

protein

- With HIV/AIDS the body has an extra need for protein. They play an important role in the body's defence system.

- Meat is a good source of protein but some people might find

it difficult to digest. Minced meat is easier to digest. Chicken and fish are good sources of protein and are easier to digest than other meat. Try out different protein sources to find out which ones are best for **you**.

- Dairy products are a good protein source. Cultured dairy products like yoghurt, lacto and cottage cheese are easier to digest than milk. If you find it difficult to digest milk because its causes cramps, a bloated feeling and sometimes rashes, you should avoid milk. It is quite possible you will not have problems with yoghurt or lacto.

vitamins and minerals

- As the body's immune system weakens, the need for vitamins and minerals increases. Fruits and vegetables are most important sources of vitamins and minerals. Eat plenty of them and vary them as different vegetables have different properties. Boiling and frying lowers the availability of vitamins to the body, therefore it is important not to overcook the vegetables. Boil or steam them for a short while in a little water.

- The skins of grains and legumes contain important vitamins. Refined grains are polished and have their skin and germ removed, leaving only the starch. Whole grains are therefore better than refined grains. Eat brown bread and unrefined maize meal (straight run) instead of white bread and super refined roller meal. Only if you have diarrhoea eat the refined products as they are easier to digest.

- Deficiency of vitamins in most cases is due to poor absorption because of an infected gut, or malnutrition, rather than its deficiency in the diet. Deficiencies occur despite

apparently adequate dietary intakes. Some people are taking multi vitamin tablets or very high dosages of some of the vitamins that are found to be deficient in people with HIV/AIDS. The usefulness of many vitamin tablets for people with HIV/AIDS however is not proven. It is not likely that the vitamins in the tablets will be absorbed. Use of vitamin tablets may create a dependency on high vitamin levels. Only when clinical deficiencies are identified, proper supplementation should be provided.

- Only vitamin A (found in all yellow, orange or red coloured fruits and vegetables, green leaves, eggs and liver) supplementation is found to be important as it is believed to reduce the risk of HIV infection from mother to child. (source AIDS ACTION no 30).
A shortage of vitamin A seems to lead to progress in HIV disease (Nutrition and AIDS). Make sure you eat enough vitamin A rich foods. If you are not able to do so ask your doctor for vitamin A tablets, especially when you are pregnant.

water

- Water makes up about 70% of the body. It is important to drink a lot of water. Water, however is often a carrier of disease causing germs. When your immune system is weakened you can get sick from water that others can drink without problems. Boiling water for at least five minutes kills germs. Keep the water stored in a container with a lid.

food safety

People with HIV/AIDS are more vulnerable to food poisoning because of their weakened immune system. Therefore strict hygienic food handling practices are very important.

guidelines for safe food handling

general

- *Always wash your hands with soap before and after touching food.*
- *Keep hot foods hot and cold foods cold.*
- *Don't eat food after the 'best before' date has expired.*
- *Be extremely careful with left-overs.* ***Do not eat left-overs*** *unless put in the fridge immediately. Store food for not more than one day and boil before eating.*

animal products

- *Cook all animal products like meat, fish, egg at high temperatures till well done because cooking destroys harmful bacteria. Do not eat soft boiled eggs!*
- *Only use plastic or formica cutting boards for cutting raw and cooked animal products. Throw away your wooden cutting boards that have been used for cutting meats etc. Wood cannot be adequately cleaned.*
- *Wash utensils and surfaces where you placed animal products before handling other foods.*
- *Put meat, poultry or fish into plastic bags before putting them into your shopping basket and put them in the bottom to stop them from dripping on other food.*

fruits and vegetables

- *Thoroughly wash fruits and vegetables that are to be eaten raw in order to remove bacteria from the skin. Cut off bruised parts. If it is not possible to wash them properly peel the skin off.*

adapted from Food for People with HIV/AIDS

Diarrhoea

When you have watery stools, more than two times a day, you have diarrhoea. Diarrhoea can be mild or serious. It can be *acute* (sudden and severe) or *chronic* (lasting many days). Diarrhoea is more common and more dangerous in poorly nourished people. Diarrhoea has many causes. Sometimes special treatment is needed. **Most diarrhoea can be treated successfully in the home,** even if you are not sure of the exact cause of the diarrhoea.

the main causes of diarrhoea

The main causes of diarrhoea are:

- poor nutrition. This weakens the person and makes diarrhoea from other causes more frequent or worse.
- virus infection or 'intestinal flu'
- an infection in the gut caused by germs like bacteria or amoebas
- worm infections
- infections outside the gut like ear infections, especially in children
- malaria
- food poisoning
- inability to digest milk (in severely malnourished people)
- side effects of certain medicines such as antibiotics
- eating too much unripe fruits
- eating greasy foods

source: Where there is no doctor

For most cases of diarrhoea no medicine is needed. If the diarrhoea is severe, the biggest danger is ***dehydration****. If the diarrhoea lasts a long time, the biggest danger is* ***malnutrition****. So the most important part of the treatment has to do with* ***enough liquids and the right food.***

It is better not to use anti-diarrhoea medicines (like immodium). These medicines, often with kaolin and pectin act like plugs; they make the diarrhoea thicker and less frequent, but do not correct dehydration or control infection. The infected material that needs to come out of the gut will stay longer in the body.

If you still want to stop the diarrhoea for some time, you can use fenugreek seeds (swallow 1 teaspoon of seeds with water). It reliefs pain and cramps and stops the diarrhoea for 12 to 24 hours.

Antibiotics are useful in cases of diarrhoea with blood or when accompanied by a fever. When there is no fever or no blood these medicines should not be used. They can make the diarrhoea worse.

It is very important to make every effort to control diarrhoea. Drink a lot of fluids to prevent dehydration and adjust your diet. Sugar-salt-solution, broth, diluted orange juice and barley or rice water are good drinks to restore the salts lost through the diarrhoea. Try out the remedies to improve digestion as presented in chapter 5, especially if you are on a treatment with antibiotics. Get medical treatment if a fever develops (for more than 6 hours), if blood appears in the stool (dysentery), if diarrhoea lasts more than 4 days and is not getting better, or if you are very sick, weak or malnourished.

Chronic diarrhoea (diarrhoea that lasts a long time or keeps coming back) is most commonly due to malabsorption. This means that the gut cannot absorb the food. You need to eat very easily digestible food. See guidelines.

diarrhoea and malnutrition

Diarrhoea and malnutrition are closely related. If you have diarrhoea you will often eat little or nothing because of the distress it is causing you. What you eat is not properly absorbed as the food does not stay long enough in the digestive system. Because of not eating enough, or not absorbing the food you eat, you get malnourished.

Malnutrition, frequent use of antibiotics (antibiotics kill the intestinal flora that help digestion), or HIV cause malabsorption. The weak intestines cannot properly absorb food and are susceptible to infections.

If the food is not properly absorbed (malabsorption) in one part of the digestive tract, it might cause problems in another part and continue the diarrhoea (as in the case of fat). Diarrhoea is dangerous, it damages your digestive tract and prevents the absorption of the nutrients you badly need.

nutrition plays an important role in treatment

Fat and **milk** are the major food items causing problems in case of malabsorption. Fat is absorbed in the small intestines. Fat is difficult to digest and intestines that are weakened by diarrhoea cannot absorb fat properly. The fat will pass to the large intestines where it will act as a laxative. More diarrhoea and weight loss will be the result.

Milk contains lactose. Damaged intestines are often intolerant to lactose. Drinking milk or eating milk products can cause cramps, abdominal distress and diarrhoea. Because of HIV you may become allergic to foods that you were not allergic to before. The proteins of milk or egg, especially the white, may cause an allergic reaction.

To break the circle of diarrhoea, malnutrition and infections, you will need to eat food that is very easily digestible. Reduce fat and avoid milk. High fibre foods, containing the skins of grains, seeds, nuts, beans and pulses should also be avoided.

As a part of the poor functioning of the digestive system, production of saliva is poor. Malnourished people need to eat soft, mashed, liquid food, as solid food is difficult to swallow.

After a period of chronic diarrhoea you have to rest the intestines and let them start working again without producing diarrhoea. This will often take at least two weeks.

guidelines in case of diarrhoea

- *Eat soft, mashed, liquid foods that are easy to eat and swallow.*
- *Eat small meals, 5 or more per day.*
- *Drink a lot to prevent dehydration.*
- *Eat food that is low in fat. Do not add cooking oil and margarine. Cut away the visible fat of meat or skin of chicken. Boil food rather than fry.*
- *Eat starchy food that is high in carbohydrates to provide energy like rice, potatoes, maize, bread.*
- *Eat refined foods like white rice, refined roller meal, white bread, pasta.*
- *Avoid milk and milk products.*
- *Eat soft fruits and vegetables like banana, paw-paw, watermelon, pumpkin, squash, potatoes and carrots. These provide the necessary vitamins and minerals.*
- *Avoid strong or acidic fruits and vegetables like onion, tomatoes and pineapple. Do not use hot spices like curry or piri-piri.*
- *Prepare vegetable soups/stews, using refined roller meal, rice, barley or potatoes with soft vegetables like squash, pumpkin or carrot. Use a whisk (kusika) or masher to mash the vegetables (see recipes).*
  Note that packets of soup are not nutritious foods. They mainly contain salt, a little flour, and artificial flavouring.
- *Start from those food items that you enjoy. Then be creative in preparing soups and meals.*
- *Prepare fresh food from fresh ingredients. Do not store prepared food and risk food poisoning.*
- *Read chapter 9 on herbs and spices for diarrhoea.*

useful recipes for diarrhoea

If you have severe diarrhoea, eat soup on its own. If diarrhoea reduces and you have more appetite eat the vegetable soups with rice or sadza. Rice is easier to digest than sadza.

rice porridge

* rice, salt, cinnamon, sugar

Boil the rice with 3 cups of water for every cup of rice. Add a little salt. Cook slowly for one hour. Add sugar and cinnamon when serving.

carrot soup

* carrots, salt, cinnamon, water

Chop carrots. Bring to boil in water and cook slowly until soft. Mash the carrots. Add a pinch of salt and ground cinnamon.

pumpkin stew

* pumpkin or butternut, beef

Boil beef with chopped pumpkin. Cook slowly until the beef and pumpkin is very soft. Mash the vegetables with a whisk or masher. Cut the beef in small pieces and add to the pumpkin.
You can boil mealie meal with the stew to add carbohydrates for energy.

rice soup

* rice, water, salt

1 cup of rice to 4 cups of water and salt. Cover the pot and cook slowly for one hour.
You can make different rice soups by adding other ingredients like:
- grated carrot and cinnamon
- finely chopped garlic, chopped liver and grated pumpkin

bean broth

* beans, salt

Boil the beans with more water than usual, until they are well cooked. Drink the bean broth or use it to make other soups. Serve the beans to family members that do not have diarrhoea.
You can boil the broth with mealie meal for more energy.

chicken soup

* chicken, squash, pasta (macaroni, spaghetti or noodles)

Boil pasta until it is very soft. Boil chicken and squash in water and salt. Cook slowly until very soft. Mash the vegetables with a whisk or masher and cut the chicken in small pieces. Add the boiled pasta.
For an exotic change add pieces of paw-paw or banana to the soup and boil a few more minutes.

potato soup

* potatoes, carrots, thyme and salt

Cut potatoes and carrots in small pieces and boil in water with salt. Cook slowly till very soft. Mash the vegetables.
For a change add some fat free minced meat to the vegetables and boil as above.

TIP: If your soup turns out too thin: mix 1 spoon of corn flour (super fine) with a little water. Add to the soup and heat till boiling.

rice or barley water

Cook 1 cup of grain in 5 cups of water with salt. When the grain is cooked strain off the excess water. Allow to cool and drink it. Add ¼ teaspoon of cinnamon powder, or sugar and a little orange juice if you like.

Weight loss and weight gain

weight loss

Weight loss is a result of not enough food. This can be a result of:

- increased need because of infections or fever
- poor absorption because of:
  diarrhoea; food does not stay long enough to be absorbed,
  malnutrition; shrinking of the gut wall,
  HIV; not exactly clear why it causes poor absorption
- not enough food:
  loss of appetite, sore mouth, vomiting, depression, poverty,
  food is not nutritious enough (not enough protein and energy)

When the body does not get enough nutrients, or cannot absorb the nutrients it gets, it must use stored reserves. Fat and carbohydrates have stores in the body, but proteins do not. The body will break down the muscles to get the needed proteins. When the muscles start to break down we speak of body wasting.

As the immune system also uses proteins for its functioning, shortage of proteins will affect its performance. The use of protein in the body explains why weight loss results in a vicious cycle of continued loss of muscle mass and weakening of the immune response. This leads to more and more prolonged infections, leading to further weakening of the body.

It is important to point out that the deficiencies are mainly in protein and energy (carbohydrates and fat), and not in vitamins and minerals.

Weight loss is serious in people with HIV/AIDS, it is a sign the disease is taking over. Serious weight loss (10% of body weight in 2 months) is generally associated with the onset of clinical AIDS.

Think of food as fuel, which is used to make your body operate. If you consume less energy than your body needs, your body will adapt to the lack of fuel and slow down its processes to conserve that fuel.

If you eat less than you need, you will:

- *feel cold, especially hands and feet*
- *get dry scaly skin and hair, body rashes and itching*
- *feel bloated, especially in the hands and feet, rings and shoes will feel tight, due to oedema or water retention*
- *suffer dizziness and light headedness*
- *have a pulse rate below 60*
- *feel depressed,*
- *feel tired and weak*

adapted from Surviving with AIDS.

weight gain

To stop weight loss we have to treat the **cause of the problem** first. Do the following:

- **stop diarrhoea** - check infections, eat easily digestible food (see chapter 3 on diarrhoea)
- **treat infections** - get medical treatment
- **adjust food intake** - eat soft liquid food if you have mouth sores, increase protein content in the diet (see chapters 5 and 9 on remedies to improve digestion)

Once the diarrhoea is under control and the infections are treated you have to stop the process of body wasting and try to reverse some of the body breakdown mechanisms. This may take a long time depending on the state of malnutrition. You should be careful with fat and slowly introduce it in your diet. Protein content of the food should be increased to try to rebuild some depleted sources. The energy content of the food should be increased by eating more carbohydrates (starchy food). See guidelines.

Weight gain involves eating well and exercising well.

exercise

Regular exercise is important to the healthy functioning of your body. It strengthens your muscles and this helps to strengthen your immunity. Exercise is the only way to build muscle, your body's way to store protein.

If you need to gain weight, then along with eating more, you also have to exercise. If you don't, the extra you eat becomes a padding of fat. That is not very helpful because you need stored protein to resist infections.

Disuse of muscle inevitably results in shrinking of the muscle and this may be a factor in muscle wasting found in AIDS patients. It is obviously possible that people living with HIV/AIDS are less

active, either because of the disease or because of change in lifestyle. This decreased activity will result in muscle loss.

Exercise also increases your appetite and personal sense of well being. Walking, jogging, swimming and dancing are good ways to exercise. Make an effort to find an exercise programme that suits you.

guidelines for weight gain

- *Introduce one new food item at a time. When it is causing problems you know what food has caused the diarrhoea.*
- *Increase protein content of the food by adding beans, peas, lentils, eggs, fish, meat etc. Add these to the vegetable soups. Split peas are good to start with as their skins are removed. Add peanut butter to your porridge.*
- *Slowly increase the fat content of your food.*
- *Increase the energy content of your food by eating a high carbohydrate and high protein diet.*
- *Carefully introduce milk products. Fermented products like lacto and yoghurt are more easily digestible.*
- *Most vegetables and fruits can be eaten. First time you eat it, just eat a little. If something causes problems, do not eat it for some time. Avocado pear, dark leafy greens, beetroots and mangoes are very nutritious.*
- *Read recommendations in chapter 6 to help digestion, especially of fats and protein.*
- *Read recommendations in chapter 9 on herbs and spices, especially those to improve digestion and appetite.*

mutakura

* cowbeans (nyemba), whole maize (magwere or chibage)

Boil maize and beans till very soft. Mash. Serve with vegetables.
Mutakura can also be prepared with peanuts instead of beans.

nhopi

* pumpkin, peanut butter

Boil 1 cup of chopped pumpkin in water with salt for 30 minutes till very soft. Add 2 tablespoons of peanut butter and mash.
Eat on its own or with sadza or rice for extra energy.
Nhopi can also be prepared adding boiled beans instead of peanut butter to the pumpkins. Mash together.

bean porridge/rupiza

* cowbeans (nyemba), peanut butter

Roast the beans and pound. Boil the pounded beans till soft. Add peanut butter and mix. Eat with boiled sweet potatoes.

high protein milk

* milk, skim milk powder

Add one heaped table spoon of skim milk powder to a cup of milk, mix thoroughly.

rice and spinach soup

* rice, spinach, peanut butter

Boil the rice with 4 cups of water for every cup of rice for 40 minutes. Add chopped spinach and 2 table spoons of peanut butter when the rice is cooked. Stir and cook slowly for 10 more minutes.

barley and vegetable soup

* barley, tomato, carrot, potato, pumpkin, leafy greens (covo, tsunga, mutikiti), or whatever vegetables you have, parsley and thyme, garlic and a squeeze of lemon.

Boil barley for 40 minutes. Chop garlic and vegetables (except the greens) and fry in little oil. Add water and cook slowly till soft. Mash vegetables. Add cooked barley, finely chopped greens and herbs. Cook for 10 more minutes.
For a change start by frying minced beef. Add in vegetables and cook as above.

pea soup

* split peas, rice, carrot, onion, salt, thyme, bay leaf, parsley

Boil split peas with rice in water and salt. Add chopped carrot and onion. Add green herbs. Cook slowly for one hour till soft. Mash stirring vigorously with a whisk (kusika) or masher.
For a change cook a piece of sausage with the soup and cut in pieces.

beef broth

* beef, water, carrot, onion, thyme, parsley, pepper, salt

Boil beef with chopped vegetables, water and spices till beef is well cooked (about 90 minutes).

white flour sauce

* 1 tablespoon of margarine, 1 tablespoon of flour, 1 cup of milk or broth (see previous recipe)

Melt butter over medium heat. Remove pan from heat and blend in flour. Return to heat and stir till cooked. Slowly add milk or broth and whisk until smooth and thickened.
Mix the sauce with the boiled beef from the broth or mix the sauce with any cooked vegetables or peas.

beef and lentil soup

* minced beef, onion, lentils, spinach or other green leaves, margarine, salt and pepper

Fry beef and chopped onion in margarine in a large saucepan. When meat is brown add lentils, chopped carrot, salt and pepper. Add water, cover and cook until lentils are tender (about 30 minutes). Add in chopped green leaves and boil another 10 minutes. When serving add a squeeze of lemon juice.
Serve as a soup or with sadza or rice.

corn and cheese chowder (easy and quick to prepare)

* 2 cups of potatoes, 1 cup of carrots, 1 cup of celery, 1 (medium size) can of cream style corn, 1 cup of grated cheese, 1 packet (500 ml) of milk, pepper and salt

Chop potatoes and vegetables. Boil slowly in 1 cup of water for 15 minutes. Add corn and simmer for 5 more minutes. Add milk and heat until boiling. Remove from heat and add grated cheese.
It is nice to add thinly chopped bacon for a change.

bean and tomato soup (easy and quick to prepare)

* 1 (medium size) can of baked beans, 1 (medium size) can of tomatoes (or 5 chopped fresh tomatoes), parsley and basil leaves, cheese

Mix the tomatoes and beans together in a saucepan. Bring to boil and boil slowly for 10 minutes. Then add freshly chopped spices. Sprinkle on grated cheese just before serving.
For a change add minced meat and boil together with the beans, or add chopped leafy greens.
Eat on its own or with sadza, rice or pasta for more energy.

peanut sauce with matemba

* 2 onions, 2 table spoons of peanut butter, ½ small packet (250 gr) of matemba, 1 packet (500 ml) of milk, salt, pepper, ginger, squeeze of lemon juice, ½ table spoon of brown sugar, margarine

Fry the chopped onions in a little margarine. Add spices and matemba and boil slowly for 10 minutes. Add peanut butter and stir in milk until thick. Add squeezed lemon juice and sugar before serving. Eat with sadza or rice.
For a change prepare the sauce without matemba. Serve with roasted meat and tomato salad.

liver soup

* liver, pumpkin, soup mixture (rice, barley, lentils and split peas), garlic, thyme, pepper, salt

Fry liver and garlic in a little margarine or oil and cut in small pieces. Add grated pumpkin, soup mixture, water, pepper, salt and thyme. Bring to boil and boil slowly for about 1 hour.
Eat liver soup on its own or with sadza if you are hungry.

mixed beans with spinach

* 1 cup of mixed beans, 4 tomatoes, spinach or other green leaves, 1 clove of garlic, 2 onions, pepper, salt.

Boil beans in water with salt. Fry chopped onions and garlic in a little margarine or oil. Add chopped tomatoes, boiled beans and bring to boil. Add chopped spinach or other green leaves, cover and boil slowly until the leaves are soft.
Eat with rice or sadza.

chapter 5

Food to improve digestion

fermented food

In our intestines live bacteria that help us to digest the food. They are called intestinal flora or friendly flora.

Antibiotics, cancer treatment, TB treatment (=antibiotics) destroy bacteria, both bad and good ones. They kill the good bacteria in our intestines. Therefore treatment with antibiotics can cause digestive problems or diarrhoea.

Fermenting makes food easier to digest. Fermented foods are also a source of friendly flora which help digestion. They are good for digestive problems, especially diarrhoea and thrush.

To restore good bacteria in the digestive tract it helps to eat cultured or fermented food products. Eat the drinks/foods listed below as a medicine, three cups a day, before or with the meals when on antibiotic treatment. Continue for two weeks.

- *sour water of sour cabbage juice (recipes below)*
- *mahewu*
- *yoghurt, unsweetened*
- *sprouts (see below for sprouting guidelines)*
- *chibuku*

sprouting

Sprouts are germinating seeds, which are starting to grow into a new plant. Sprouting increases the vitamin, mineral and protein content of the food that you germinate.

Method

- Soak seeds for 6-12 hours and drain off water.
- Keep the seeds in an open container (jam jar), cover with mosquito mesh or cheese cloth.
- Rinse (add water and drain off) three times a day or more when hot.
- When ready add to soups, stews, salads, or have on bread.

	amount	**soak**	**grow**
lentils	1 cup	12 hours	2-4 days
mung beans	1/2 cup	12 hours	2-4 days (dark)
sesame	1 cup	6 hours	1-2 days (eat small)
wheat	1 cup	12 hours	2-3 days
maize	1 cup	12 hours	3-4 days

source Food for people with HIV/AIDS

Other food to improve digestion

- Lemon and orange skin contain pectin. It helps to absorb fat. Add grated skin to your soups and stews. You can also add it to your flour when baking biscuits or cakes.
- Lemon juice helps the digestion of fat. Squeeze some lemon juice in your soups and stews.
- Paw-paw helps to improve the digestion of meat protein. Add chopped paw-paw to dishes with meat.
- Read chapter 9 on herbs and spices to improve digestion.

Sour water and sour cabbage water is good for diarrhoea, thrush and ulcers and helps digestion when on antibiotic treatment. Sour water has a strong smell.

sour water

* use any grain, millet, sorghum or barley

Wash the grain and soak 1 cup of grain with 3 cups of boiled and cooled water. Cover tightly in a plastic container and leave for 2-3 days. The sour water is ready when it forms bubbles. Strain the water and keep in a cool place. A second and third batch of sour water can be made from the same grain. Add new boiled and cooled water. After 1 day it will be ready.

sour cabbage water

* finely chopped raw cabbage

Soak 1 cup of chopped cabbage with 3 cups of boiled and cooled water. Cover tightly in a plastic container and leave for 2 days. Strain the water and keep it in a cool place. A second batch can be made from the same cabbage. Add new boiled and cooled water, it will be ready after 1 day. After using the cabbage twice you can not use it again for more sour water.

You can boil the cabbage with a little salt and chopped banana or apple. Eat with mashed potatoes.

ginger drink

* 8 cups of clean warm water, 3 teaspoons of ginger, 2 teaspoons of sugar, 1 small chopped pineapple

Mix all ingredients and leave in a warm place for 1 day. Drink the ginger juice. You can eat the pineapple.

Colds, flu and cough

Colds and flu

Colds and flu are common virus infections that may cause runny nose, cough, sore throat and sometimes fever. Colds and flu almost always go away without medicine. It is not necessary to use penicillin, or other antibiotics, as they will not help.

- Drink plenty of water and get enough rest.
- Paracetamol helps to lower fever and relieves headaches.
- No special diet is needed. However fruit juices like orange juice are helpful.
- Use a handkerchief when sneezing to prevent infecting others, and stay away from small babies.

If a cold lasts more than a week, or if a person has fever, or coughs up a lot of mucus, see a doctor as an antibiotic may be needed.

Coughing is not a sickness by itself but a sign of many different sicknesses that affect the throat or lungs. Coughing is the body's way of cleaning the breathing system and getting rid of mucus and germs in the throat or lungs. So when a cough produces mucus, **don't take medicine to stop the cough, rather do something to help loosen and bring up the mucus.**

to loosen the mucus:

- *Drink lots of water.*
- *Breath hot vapours. Take a pot with very hot water and cover your head with a towel. Breath the vapours deeply for 10 minutes, two times a day. You can add eucalyptus (gum), mint or thyme leaves or vaporub, but hot water works just as well alone.*
- *Onions are good for colds, cough and blocked noses. Before going to sleep cut an onion in pieces and put them next to your bed.*
- *Prepare teas against coughs. See recipes below.*
- *Prepare plant extracts (tinctures). See recipes below.*
- *Prepare cough syrups.*

- Cough syrup for adults

Mix one part of honey with one part of lemon juice and one part of cane spirit 40%. Shake or stir well.

- Cough syrup for children

Mix one part of honey with one part of lemon juice. Shake or stir well.

- Cough syrup with plant extract

Add 30 ml of lemon juice in a clean 100 ml bottle. Add plant extract: 20 ml for adults, 10 ml for children. Fill up the bottle with honey. Close the bottle and shake well. Use a large syringe (without a needle, from the pharmacy) to measure the amounts.

recipes for colds

onion tea for blocked and runny noses

Put one quarter of an onion in a cup of boiling water. Cover and leave for 5 minutes. Strain. Drink 1 cup three times a day.

ginger-cinnamon tea for chesty colds

Add ½ teaspoon of chopped fresh ginger to 1 cup of boiling water. Boil slowly for 10 minutes. Add ¼ teaspoon of ground cinnamon. Cover and allow to stand for 5 minutes. Strain the tea. Drink 1 cup three times a day. Start taking the tea as soon as you feel the cold coming.

thyme tea for dry cough

Add ¼ teaspoon of dried thyme leaves to 1 cup of boiling water. Cover and leave for 5 minutes. Strain the tea. Drink 1 cup three times a day.

guava tea for persistent cough

Add one guava, one lemon and one eucalyptus leaf to 1 cup of boiling water. Cover and allow to stand for 5 minutes. Take a sip three times a day.

lemon tea for flu

Squeeze a lemon. Add the juice to ½ cup of boiling water. Add sugar if you like. Drink as hot as possible, 1 cup three times a day.

eucalyptus extract for sore throat

Fill up an empty beer bottle with leaves of eucalyptus (gum tree). Press well with a knitting needle or stick to get in as many leaves as possible. Fill up with alcohol 40% (for example cane spirit). Press with the knitting needle to get the air out. Close the bottle. Leave in a dark place for two weeks. Strain off the alcohol/plant extract.

Use 3 drops of extract on the back of the tongue in case of a sore throat. It disinfects the throat. Start using the extract as soon as you feel a sore throat coming. Continue using the drops every 2-3 hours until you feel no more pain. You can use the extract to prepare cough syrup.

thyme extract for sore throat

Use 20 grams of dried thyme leaves (1 refill packet). Add 100 ml of alcohol 40% (for example cane spirit). Keep in a closed bottle in a dark place for two weeks. Strain off the alcohol.

Use 3 drops of extract on the back of the tongue in case of a sore throat. Thyme has antiseptic properties. Start using the extract as soon as you feel a sore throat coming. Continue using the drops every 2-3 hours until you feel no more pain.

You can also use the extract to prepare cough syrup.

Sore mouth

sore mouth

A sore mouth is caused by infections in the mouth. Although eating is more difficult, the need for nutrients is higher because of the infection. It is important to adjust the food you eat in order to get enough food and prevent weight loss.

guidelines for mouth sores

Avoid foods that irritate like:

- *spicy foods: chilies, curries*
- *acid foods: oranges, pineapple, vinegar and bottled soft drinks*
- *foods that need a lot of chewing*
- *foods that are sticky like white bread with peanut butter*
- *very hot and very cold food*

For relief:

- *chew on a piece of tomato, green mango or chonjwa leaves. This helps to relieve the pain and you can then eat your food.*
- *eat soft mashed foods, like avocados, squash, pumpkin, yoghurt, mince, paw-paw and bananas.*
- *drink nutrient rich liquids such as vegetable juices, soups and fruit juices.*
- *rinse your mouth with cinnamon tea. ¼ teaspoon of powdered cinnamon in 1 cup of boiling water. Cover and allow to cool.*
- *rinse your mouth with garlic tea. 2 chopped cloves in 1 cup of boiling water. Cover and allow to cool.*

candida/thrush

Candida is a yeast infection. An outbreak of candida is a sign of poor resistance. It shows as **thrush** in the mouth with white spots on the gums and on the sides of the tongue, burning swelling and redness of the mouth. This not only causes taste changes but can also be responsible for pain when eating and swallowing. Thrush can also occur in the vagina. In the bowel it causes poor absorption and weakness.

guidelines for candida

- *Try thyme tea, as mouth wash, or pour it into your vagina*
- *Try to increase body temperature by eating more protein rich food. Temperature may be low because of eating too little food.*
- *Use warming spices as cinnamon, ginger or rosemary. Prepare teas or use the spices when cooking your food.*
- *Use garlic:*
  - in the mouth: It is best to chew the peeled clove.
  - in the vagina: Insert a whole peeled crushed clove.
  - in the bowel: Swallow a crushed clove as a pill or make garlic tea: Chop 2 cloves of garlic. Bring to boil with 1 cup of water and boil slowly for 5 minutes. Add parsley if you wish.

Use of garlic helps for many infections such as candida, herpes, gut infection. When you have an infection take 5-6 cloves per day, for 3-4 days. For example 1 cup of garlic tea with 2 cloves three times a day. Or just chew the cloves and swallow.

To prevent infections use 1 clove of garlic every day!

Skin problems

Skin problems

Some skin problems are caused by diseases that affect the skin like ringworm, or warts. Other skin problems are signs of diseases that affect the whole body such as rash of measles or sore dry patches of pellagra caused by undernutrition. Certain kinds of sores or skin conditions may be signs of serious diseases like TB or syphilis. Candida and Herpes Zoster are signs of poor immune response.

Poor skin condition can be caused by lack of vitamin A (found in yellow and orange vegetables, green vegetables, liver and garlic) or vitamin B6 (found in germ, whole grains, seeds and nuts, banana and green leafy vegetables).

Although many skin problems need specific treatment, there are general measures that often help.

guidelines for skin problems

- *If the area is hot and painful:*
  - treat it with heat. Put hot moist cloths on it. Raise the affected area.
- *If the area itches:*
  - treat it with cold. Put cold wet cloths on it.
  - apply slices of tomato, leave for one hour, then allow the affected skin to dry. Next morning rinse gently with clean water. Continue every day until improvement.
  - tie the skin of paw-paw fruits on the area.
- *If the area is usually exposed to the sun:*
  - cover it against sunlight (long sleeves, hat).
- *If the area is normally covered with clothes:*
  - expose it to sunlight, for 20 minutes 2 or 3 times a day.
- *In case of open wounds:*
  - apply the slime of aloe (gavakava) by pressing a freshly cut part of the plant on the wounds (also in case of herpes). When the wound is infected rub the plant in the wound to clear the puss.
- *Herpes zoster can be suppressed by eating oats porridge daily.*
- *An itchy skin can be a sign of weight loss. Read chapter 4 on weight gain.*

Herbs and spices

cooking with herbs and spices

Spices add flavour to food. They also have strong medicinal properties that can help to heal. Spices:

- stimulate the appetite
- assist digestion
- preserve foods
- help with ailments of the digestive tract

Spices are better to use than bought seasonings and stock cubes, which contain artificial flavours and chemicals that stress the immune system. Spices generally work to improve digestion. Asian shops that buy in bulk and repack themselves often sell spices at reasonable prices. Some people consider the use of herbs or spices an increase in the price of food, but compared to medicines they are cheap. Teas are a good way of taking herbs and spices as a medicine. Strain the teas before drinking.

preparation of herb teas

barks, roots, seeds	*Crush the material. Bring to boil in water. Cover and boil slowly for 10 minutes (decoction).*
fresh leaves	*Put 1 tablespoon of chopped leaves in a cup. Add boiling water. Cover and wrap in a towel. Leave for 5 minutes (infusion).*
dried leaves	*Put ½ tablespoon of leaves in a cup. Add boiling water. Cover and wrap in a towel. Leave for 10 minutes.*
powdered seeds or bark	*Put ¼ teaspoon of powder in a cup. Add 1 cup of boiling water. Cover and leave for 5 minutes.*

warming remedies

Warming remedies open the blood vessels and improve the circulation in the body. By doing so they generally activate most processes in the body, including the immune system. Warming herbs should be used for **colds** and to **stimulate digestion**. Use the warming spices when preparing your food, or prepare teas. Warming herbs should **not** be used for weak and feverish people as it will exhaust them. Do not take warming herbs in hot weather. Below are some common warming remedies.

cinnamon

Cinnamon is used specifically for conditions with symptoms of feeling cold, poor circulation to the extremities, swelling (oedema), diarrhoea and loss of appetite. It is used for chest infections, especially in combination with ginger. Cinnamon gently stimulates digestive juices and encourages effective bowel movements.

garlic

Garlic helps to fight infections caused by viruses, bacteria and fungi, especially in the gut and in the lungs. Garlic stimulates digestive juices and gut activities. Garlic reduces blood pressure. Garlic is good for thrush and throat infections (crush the clove in your mouth), for herpes and diarrhoea. Garlic, if taken daily can protect against infections. Garlic does not harm the intestinal flora. The smell of garlic on the breath is reduced when it is used together with parsley.

ginger

Fresh ginger root is used to treat common colds. The powdered ginger is more active on the gut. It is used to relieve nausea and vomiting. It is also used for a cold feeling in the tummy. Ginger can assist to return normal menstrual flow in women.

cardamon

Cardamon seeds are a warming remedy for digestive problems with pain, diarrhoea, nausea, vomiting and loss of appetite. Cardamon is valuable where poor digestion and absorption seem to be the reason for chronic weakness. Cardamon is less stimulating than the above herbs, therefore the risk of exhaustion is less.

eucalyptus/gum

The oils in eucalyptus leaves have a warming effect as they provoke increased blood flow to reduce the symptoms of the inflammation. The leaves are used in vapours for colds. Eucalyptus tinctures (alcohol extracts) are used for sore throats and in cough syrup.

cooling remedies

Cooling remedies reduce the vital activities, and reduce inflammation, pain and tension. Cooling remedies have restoring properties. Cooling remedies should **not** be used in very weak people.

The bitter cooling remedies are used for inflammatory and digestive disorders such as jaundice, loss of appetite, poor digestion and food intolerance.

The relaxing cooling remedies reduce the symptoms of tension.

Use the cooling spices when preparing your food, or prepare teas.

Below are some common cooling remedies.

dandelion

Dandelion is a bitter cooling remedy used in jaundice to restore liver activity. It has similar effect on gall and spleen.

turmeric/yellow root

Turmeric or yellow root is a bitter digestive stimulant. It helps in healing of the gut wall and other mucous membranes like the stomach, mouth and gums. It can be used in cases of diarrhoea especially if there is inflammation of the upper gut wall. It also provokes a healthy bowel movement.

mint

Mint or peppermint is a cooling relaxant, used to reduce colic (abdominal pain, cramps), to control diarrhoea and to stop vomiting. Mint relaxes and therefore is used for tension and sleeplessness. Mint regulates menstrual periods that are too heavy.

other remedies

thyme

Thyme has antiseptic and antifungal properties. It relaxes nervous coughing and increases mucosal secretions. Thyme stimulates digestion and stimulates the growth of intestinal flora in the gut. Thyme is used as a gargle or mouthwash, or as a vaginal douche. As a tea thyme is most effective in the gut.

parsley

Parsley leaves reduce intestinal colic. Parsley stimulates stomach secretions and activity and therefore produces a feeling of hunger. The seed is used to remove excess water from the body. Also it brings on suppressed menstruation.

calendula

The essential action of calendula flower heads is antiseptic, anti-inflammatory and healing. As a compress it is used to help healing and on infected wounds.

In the gut calendula is helpful for infections in the upper digestive tract. Prepare tea.

Check your weight every week!

date	weight	reason weight gain or loss

4

MATERIAL ON HIV/AIDS

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A Guide for Trainers

World Health Organization
Regional Office for South-East Asia
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PREFACE

In the South-East Asia Region, the alarming spread of HIV infection and the increasing numbers of persons with AIDS is posing an unprecedented challenge to all those involved with the medical, social, economic, ethical and legal aspects of this devastating pandemic.

While surveillance, blood safety and information and education programmes are well under way in all Member countries of the Region, counselling services for HIV/AIDS are yet to develop significantly. This is largely due to lack of trained counsellors available in the countries.

The importance and place of counselling in AIDS prevention and control programmes can no longer be ignored. More and more HIV infected individuals and persons with AIDS are needing help to enable them to live a life of dignity and to prevent the spread of infection. Counselling is also urgent for those being tested for HIV and for those with past or current risk behaviour, or living with the knowledge that they are HIV positive.

Today it is well recognized that counselling is not only part of good clinical management and care, but it is also vital for preventing the transmission of HIV infection.

The Modules presented in this Guide are adapted from the HIV/AIDS Counselling training materials being developed by the Global Programme on AIDS, WHO Headquarters. The Guide has been developed for use in the South-East Asia Region.

The Modules are designed to train HIV/AIDS care providers as for example, nurses and social workers in hospitals, health centres and other health and welfare facilities, both in the governmental and nongovernmental sectors, and to be used by a team of resource persons who have counselling experience as well as experience in inservice training of health and social workers.

Following a review of the Modules at a South-East Asia Intercountry Workshop in March 1993, the Modules were field-tested in Nepal in October 1993 and revised. If found necessary, further adaptation of the Guide could be undertaken in the countries to meet the local and culture-specific counselling needs of persons affected by HIV infection and AIDS.

Dr Uton Muchtar Rafei
Regional Director

ACKNOWLEDGEMENTS

This document, "An Orientation to HIV/AIDS Counselling: A Guide for Trainers", is the result of joint efforts by many partners.

Main contributions were made by Dr Shankar Chowdhary in the preparation of the document. Useful inputs were also provided by Dr Indira Kapoor.

Valuable suggestions were also made by the participants from nine Member Countries of WHO's South-East Asia Region at the Intercountry Workshop on Training in Skills to Develop HIV/AIDS Counselling Training and Services, held in India in March 1993.

The document was further revised by Ms Jasmeet Kaur after the training Modules were field tested in Nepal in October 1993.

Several staff members both from WHO Headquarters and from the South-East Asia Regional Office gave their time to review the materials, field test and provide technical guidance throughout the development of this document.

All contributions are gratefully acknowledged.

NOTES FOR THE USER OF THIS GUIDE

INTRODUCTION

An orientation to HIV/AIDS Counselling: A Guide for Trainers has been designed to help trainers who are asked to organize a training programme for HIV/AIDS counsellors. It is an introductory programme or orientation to counselling. Having completed the programme, the trainees should be encouraged to practice the skills they have learned over a significantly long period. The counselling they do may be in their workplace, in a health facility, or in their own community. The Guide has been designed for use in the South East Asia Region. It comprises seven Modules extracted largely from WHO documents. To each Module is annexed Trainers resource materials (supplementary reading).

THE TARGET AUDIENCE

This Guide has been designed to help almost anybody become a counsellor. The workshop trainers or facilitators should be either *counsellors* with experience in talking to/working with clients, or *teachers/trainers* who are familiar with using experiential forms of teaching. An essential criteria for selecting the trainers needs to be the ability to ask open-ended exploratory questions and sensitivity towards involving each and every trainee. The trainees could be primarily health professionals who are dealing with HIV/AIDS in their work; health workers interested in developing some skills in counselling from both governmental and non-governmental organizations. Trainees may also include staff from other sectors, such as social work, staff of de-addiction centers, teachers etc who need to learn more about HIV/AIDS to assist them in their current work; or community workers and leaders who are active in community development programmes. Those involved in dealing with STDs in their work would also find this Guide helpful.

FOLLOW UP TRAINING

Orientation and some basic skill building for counselling is only the first of several steps. Counsellors need the opportunity to practice their skills over a period of time. Not only is practice needed, but also the opportunity to discuss how they are doing with a supervisor or a colleague, and sharing new or different ideas with other counsellors. As a trainer it is crucial that this important stage of practising skills is recognized and encouraged.

Some counsellors may want to participate in more training to develop the skills to counsel more difficult cases, or where they are spending a lot of time counselling and need some additional skills. This is a further stage of training for which different materials and methods are needed.

SETTING THE STAGE FOR THE WORKSHOP

It will be useful to consider the following while planning for the workshop:

AWARENESS OF LOCAL/COUNTRY SETTING

Counsellors need to be well-informed about all the services from which they can draw resources for support, control and prevention. The *resources available* will vary from place to place; the way in which

they are mobilized will also vary depending on cultural, political and economic factors. Ideally, before each training workshop, all counsellors should examine what local resources do exist. It may be helpful for the trainers or organizers to do some background research on locally existing resources before the workshop begins and incorporate the information in the training. Such services or resources include:

- local health authorities responsible for the HIV/AIDS prevention and control.
- health educators, especially those who serve remote or isolated areas;
- specialist and general or family medical practitioners, public health medical officers, and hospital staff;
- staff of STD clinics;
- nurses and midwives, particularly those attached to communities and health centres, but also institutional staff;
- maintenance and auxiliary staff in hospitals and clinics;
- professional and support staff in community health and mental health centers, Red Cross and Red Crescent societies, and correctional institutions;
- traditional healers and birth attendants;
- trained, private or officially appointed counsellors;
- personnel of government ministries of health and education;
- teachers, school health staff, student health staff and counsellors;
- staff of drug de-addiction centers
- national, regional and local research organizations;
- non-governmental organizations, voluntary organizations, including religious, civic, political, self-help groups and women's organizations;
- community leaders and other influential people;
- staff of agricultural extension and leadership development programmes; and
- information-dissemination and education-oriented organizations/sources.

It would be critical and impactful to ensure that the appropriate health authorities of the region/district be invited to the inauguration at the beginning of the workshop. They should be requested or briefed to give a general overview of AIDS programmes, government policies and testing facilities/procedures in the region.

ORGANIZING THE PROGRAMME

The 7 Modules should be taught 1–7, although some trainee counsellors may not need to complete every Module if they already have some skills in counselling or know a lot about HIV. It is possible to complete the whole programme in four days, although this means very intense training sessions for trainers and trainees. It is also possible to use the Modules in a less concentrated way, and spend half a day each week, or one evening a week as in-service or on-the-job training with small groups of trainees. As the organizer of the training, you will need to have a large enough room to accommodate the trainees, an overhead projector, and a slide projector. Flip charts or black boards will be needed to record the group ideas, and some copies of the exercises and work sheets need to be prepared before each session so that the session can continue smoothly. If possible, during the training, seating should be arranged in a circular or horseshoe configuration so that all the trainees can see their classmates. These seating arrangements promote a more relaxed environment as well as facilitate interaction.

The workshop should start with a series of discussions aimed at informing the participants about the medical, social, psychological and political aspects of the worldwide crisis created by HIV, AIDS and related diseases. If possible, any available video produced by international organizations should be screened.

Each day should begin with a plenary session designed to review factual information, research reports, or elaborations of themes/topics covered in the Guide.

Each day should end with a review of that day's plenary and group activities.

Translations and usage of local language and terminology should be done simultaneously when the workshop is in cultural settings where the trainees are *more* conversant with their local language. Time additions for such bilingual circumstances should be made accordingly, for each activity in the various sessions.

TRAINERS' RESPONSIBILITIES

As with other sensitive topics, the training Modules must be approached carefully. While using the Modules the emphasis must be on learning counselling *by doing* rather than through formal lectures or reading. The trainers must be aware of the understanding level of the trainees and be able to adjust activities accordingly. They will also need to be very familiar with the material being taught. As a facilitator, it will be your job to answer questions, talk with participants about exercises, lead group discussions, and generally give participants any help they need to successfully complete the course.

As a trainer, you will need to do three basic things: ***instruct, motivate, and manage***. To do these things, you need to begin by demonstrating enthusiasm for the topics covered in the course and for the work that the participants are doing, and by being receptive to each participant's questions and needs. Acknowledge all the trainees' responses and encourage everyone to participate in the discussions. Pay special attention to the quieter participants by directing questions to them specifically. During activities where there are sub-groups, request the chairperson/recorder of each small group to encourage discussion and inputs by *all* members of their group. At the end of each exercise or activity, it is essential to de-brief and process the experience with the full group so as to ensure complete/effective learning by the trainees.

As a facilitator you should encourage the participants to come to you at any time with questions or comments. You should always be accessible during scheduled times, and avoid working on other projects or carrying on discussions not related to the workshop during those times.

Try to promote a friendly, cooperative relationship. Respond positively to questions by saying, for e.g., "Yes, I see what you mean", or "That is a good question". You should also avoid using facial expressions or making comments that could cause participants to feel ridiculed. Finally, don't always wait for participants to ask for help. Instead, watch the participants as they work, and offer individual help if you see a participant looking troubled, staring into space, not working on activities, not writing answers, or not turning pages.

EVALUATION METHOD

Each Module provides a worksheet which consists of a few review questions for evaluating trainees performance on stated objectives. Review questions thus serve as a tool to assess trainees participation and learning from each Module.

GLOSSARY OF TRAINING TERMS

This training Guide incorporates a variety of instructional strategies to interest and involve trainees. A glossary of the following terms are explained below to facilitate the trainer's understanding:

Module: A Module is the basic unit of this training Guide which covers a specific topic. It includes the objective, the training method, reading material and review questions. Each of the Modules is compatible with the others but may also stand alone.

Objectives: An objective is a statement of purpose for each Module.

Brainstorming: It is an activity used to open a discussion on an issue or to stimulate the group. Trainees are asked to give their ideas and opinion on a specific topic, while other trainees are asked not to pass judgement on those opinions. The trainer's responsibility is to list everything that is said on the blackboard or flip chart. The trainer should also keep in mind the important points of the topic and assist the participants in bringing them out, i.e. guide the brainstorming so that the main points are covered.

The aim is to continue to explore until all ideas have been exhausted or a predetermined time limit has been reached.

Activities: An activity is a set of specific functions or experiential exercises carried out by the trainees together with the trainer in order to achieve the objectives.

Group work: Group work is an activity carried out by a small group of trainees through pooling their collective thoughts, experiences and knowledge together in order to perform a given task. Nearly all the Modules in this manual include some form of group work. It is important for the trainer to make sure that the groups of participants working together over the course of the workshop are constantly changing. The trainer will need to develop and organize a means to maintain the rotation of participants.

Group Discussion: Group discussion is a process that uses the group to disseminate information, analyze ideas or teach concepts. The process serves to increase trainee interaction among peers. The size of the groups depends on the nature of the lesson and make up of trainees.

Case study: A case study is a story that can be analyzed, and from which learning can occur. It is an interesting way to present content and encourage trainee involvement.

Role Plays: Role play is an activity which involves trainees in learning desired concepts or practising certain behaviours. One trainee takes the role of a counsellor and another takes the role of a client. Together they act a given counselling situation. Allow trainees time to decide the action of the role play. Props can be used to make the role-play more interesting and realistic. Role plays can be highly motivating because they actively involve the trainees. There are many role play situations in this Guide.

The trainer should try to ensure as many different people get to role play as the "counsellor" so that more participants can practice the skills and activities in the various role plays.

Mini-Lecture: Mini-Lecture is utilized in this guide to disseminate information

Presentation: Directly from the trainer to trainees. This method when combined with other instructional strategies, promotes greater motivation and learning.

Overhead: Overhead transparency materials are provided for use as visual aids

Transparencies: Throughout the Modules to present and review information and graphics examples. Overhead transparencies are transparent acetate sheets on which information is projected through an overhead projector. The trainer can photocopy the material provided at the end of each module, on to acetate sheets and use them during the relevant activities. He/she should also use any other visual aids/slide sets which may be available at a particular training site.

Worksheet : A worksheet is training material with specific instructions for use by trainees, which is handed out to the trainees with an aim to sensitize them on a particular topic, or evaluate their knowledge of the same.

Review Questions : Review questions are questions intended to assess trainees intake of knowledge covered during the sessions. Each Module has one set of review questions at the end.

MODULE 1

BASIC INFORMATION ON STD/HIV

MODULE 1

BASIC INFORMATION ON STD/HIV

Objective: To provide trainees with a basic understanding of HIV transmission, disease progression and the role of STDs in HIV transmission along with information about prevention.

Time to complete Module: 3 hours.

SUMMARY OF ACTIVITIES

(1) Individual exercise: AIDS Quiz.
(2) Brainstorming: Learning about HIV and STDs.
(3) Small group work: Rank the risk exercise.
(4) Presentation: Prevention.
(5) Review or summary.
(6) Assessment: Fill in the blanks exercise.

Activity 1: AIDS QUIZ (15 minutes)

Ask trainees to complete the quiz given in worksheet 1, by themselves. As they complete the quiz, ask them to keep the paper with themselves for later use.

Activity 2: BRAINSTORMING: LEARNING ABOUT HIV & STDs (1 hour 15 minutes)

This activity is designed to improve the trainees' knowledge about HIV and STDs. The trainer leads the trainees through a brainstorming exercise, where information about HIV is discussed using lead questions one by one. These questions (formulated out of the material content of the supplementary reading section) are as follows:

(1) What do the letters "A" "I" "D" "S" stand for? And what do the words mean?
(2) What do the letters "H" "I" "V" stand for? And what do the words mean?
(3) How does the body's immunity work?
(4) How does HIV affect the body's immunity?
(5) What is the natural history of HIV?
(6) How is HIV transmitted?
(7) Which STDs do you know of? Give the names and brief meanings.
(8) How do STDs affect HIV transmission?

Allow 1 hour for this brainstorming. The trainees are then asked to pull out their quiz responses of activity 1 and compare and discuss their answers with another trainee for 15 minutes. Trainer summarizes the main points of the discussion.

Activity 3: SMALL GROUP WORK: RANKING EXERCISE (20 minutes)

This activity is designed to give trainees the opportunity to apply what they now know about HIV transmission by examining the behaviours that might place them at risk. Ask the trainees to complete individually the `Rank the Risk' exercise given in worksheet 2. They may rank from 1-10 (1 means having the highest risk for getting AIDS, and 10 means having the least). Ask them to compare the answers in pairs or small groups. Note that there will be variation in responses. *The trainer summarizes by highlighting that "It is not who the individual is but rather what an individual does that puts him/her at risk"*. Allow 20 minutes.

Activity 4: PRESENTATION: PREVENTION OF INFECTION (15 minutes)

The trainer gives a short presentation on methods and issues related to prevention of HIV infection and STDs using the material provided in the supplementary reading section. The main points to be highlighted are:

(a) Prevention of sexual transmission of the disease by information/education on safer sex options and use of condoms.
(b) Prevention of blood transmission (via tested blood and sterile needles and equipments).
(c) Prevention of mother-to-infant spread of virus (viz. prevention of infection to childbearing women, avoidance of pregnancy and termination of pregnancy).

Activity 5: SUMMARY ACTIVITY (30 minutes)

Instead of the trainer summarizing for the trainees, the trainer asks for 3 pairs of volunteers. In each pair, one person plays the role of the counsellor, and the other that of the client. The counsellor explains to the client in each pair information dealing with one of the three statements below. The language used should be the vernacular with simple non-medical terms.

(a) Basic information about HIV (Pair # 1)
(b) Modes of transmission (Pair # 2)
(c) Relationship to Sexually Transmitted Diseases (Pair # 3)

The client may ask questions as necessary. Other group members observe and give a feed back. Each pair does its role play for 10 minutes. Allow 30 minutes for this activity.

Activity 6: ASSESSMENT (20 minutes)

The trainees are asked to complete the "Fill in the blanks" exercise given in worksheet 3 individually. This allows the trainees to see how much more they now know about HIV and its relationship with STDs. The trainer reads out the correct, completed exercise. Allow about 20 minutes for this activity.

WORKSHEET 1

AIDS QUIZ

To answer the questions circle the response you think is most correct.

(1) What is the complete term for AIDS & HIV?

_____

_____

(2) Which of the following is a way HIV can be transmitted?

(a) Having unprotected sexual intercourse with an infected partner
(b) Donating blood
(c) Using public toilets

(3) You can get HIV from:

(a) Mosquito bites
(b) Sharing food
(c) Hugging someone with AIDS
(d) All of the above
(e) None of the above

(4) For which of the following purposes do people share needles:

(a) Tattooing
(b) Steroid injections
(c) Injecting drugs
(d) Ear piercing
(e) All of the above

(5) One can generally identify a person with HIV infection by looking at him/her.

True ☐ False ☐

(6) Anyone who has unprotected sexual intercourse is at risk of HIV infection.

True ☐ False ☐

(7) A pregnant woman infected with HIV might pass the infection to her unborn child.

True ☐ False ☐

(8) Using an unsterilized injection needle may spread HIV infection.

True ☐ False ☐

(9) Tested blood should be used for transfusion.

True ☐ False ☐

(10) The primary modes of transmission of HIV are:

(a) _____

(b) _____

(c) _____

(d) _____

(11) The main ways of preventing HIV transmission are:

(a) _____

(b) _____

(c) _____

(d) _____

(12) AIDS is primarily seen in which of the age groups:

(a) 0-5 yrs
(b) 6-14 yrs
(c) 15-49 yrs
(d) 50-70 yrs

(13) Condoms, when properly used, can help protect you from HIV.

True ☐ False ☐

(14) AIDS can be cured if detected early.

True ☐ False ☐

(15) Would you send your child to school if you knew that the teacher was HIV positive?

Yes ☐ No ☐

(16) Mention three common STDs.

(a) _____

(b) _____

(c) _____

(17) How can you prevent STD transmission?

_____

_____

(18) If one has STD, the chances of getting HIV infection are high.

True ☐ False ☐

(19) Women are more at risk of getting HIV infection through sexual intercourse.

True ☐ False ☐

WORKSHEET 2

RANK THE RISK EXERCISE

WHO OF THE FOLLOWING HAS THE GREATEST OR LEAST RISK OF CONTRACTING HIV?

Rank from 1 – 10 (1 means having the highest risk for getting HIV and 10 means having the lowest risk for getting AIDS). The same rank can be given to more than one person listed below. *Please remember that it is not what you are but what you do that puts you at risk of getting HIV infection.*

____ School student with a classmate who has AIDS

____ Medical doctor

____ Family member of a person with AIDS

____ Someone with multiple sex partners

____ Traditional healer

____ The unborn child of an infected mother

____ Nurse

____ Sex worker

____ Voluntary blood donor

____ Intravenous drug user

____ Person with STD

WORKSHEET 3

FILL IN THE BLANKS EXERCISE

DIRECTIONS:

Use the following words to complete the paragraph below. Each word is used only once.

Understanding	Safe
Blood	AIDS
Flu	Catch
Body fluids	Immune
Virus	Person
System	Tears
Disease	Cure
Learn	Cold

..... is a communicable disease. A communicable disease is one that can be spread from ..... to person. The disease is caused by a ..... The AIDS virus is spread from person to person by sharing of ..... Body fluids include ..... and semen. Other body fluids are urine, saliva, and ..... The body fluids which spread the AIDS virus are blood, semen, and vaginal secretions.

The AIDS virus is different from the viruses that can cause a ..... or the ..... The AIDS virus is not like the cold and flu viruses because it is more difficult to ".....".

Our body's ..... system works to fight off the cold and flu. The AIDS virus is difficult because it attacks the body's immune ..... AIDS is a serious ..... There is not yet a ..... for the disease. The most important thing to do to prevent the spread of AIDS is to ..... about the disease and how it spreads.

After we learn about how the disease is spread, then we must practice ..... lifestyle behaviours.

Another important thing to remember is that a person who has the AIDS virus is a person who still needs our help and .....

Supplementary Reading

Basic Information on STD/HIV

BASIC INFORMATION ON STD/HIV

Counsellors must know the basic facts about HIV infection and its manifestations. Knowledge of the causes and epidemiology of HIV infection, AIDS and related diseases is increasing rapidly and busy counsellors find it hard to keep abreast of it. Good counsellors will be aware of the limits of their knowledge. National AIDS control and prevention programmes should provide for workshops and other methods of keeping counsellors and health workers up to date.

The information presented here will be very familiar to some workshop participants, and useful primarily for review purposes. For others, however, it will be new, and doubtless, insufficient so that additional resources will have to be made available. Both groups should keep in mind, while reading and thinking about this basic information, how they would talk about symptoms and infections to people from their own country or region, and to persons from a variety of cultural backgrounds and traditions. The San Francisco AIDS Foundation has explained the acronym AIDS in a way that may be helpful when talking to concerned or affected people, families and others (see box).

AIDS stands for:

Acquired	–	not born with
Immune	–	body's defence system
Deficiency	–	not working properly
Syndrome	–	a group of signs and symptoms

As evident by its name, AIDS is not a single disease but a syndrome - a set of diseases, which results from the destruction of the body's defences by the Human Immunodeficiency Virus-HIV.

In healthy individuals, infections and cancers are kept away by a variety of defenders in the body, which constitute its immune system. Unknown to us, these defenders are at work everyday, recognizing foreign bodies (eg.bacteria, virus etc) and fighting them with an array of cells and by producing specific chemicals called antiboidies which neutralizes the foreign bodies. Each disease stimulates the production of antibodies specific to it. The detection of these antibodies in blood samples is therefore used to determine past or present infection.

Because HIV causes damage to the immune system, the antibodies detected in the blood of the carriers of the HIV are ineffective in halting the damage caused by the virus, which may be present in large numbers in the body. Therefore, the body cannot be protected against other infections and cancers, some of which then form the direct causes of death. Because of the way that the virus infects cells, developing a cure or vaccine is extremely difficult.

1. THE NATURE OF THE VIRUS

The first cases of AIDS were recognized in the United States in 1981. The virus that causes it, now called HIV, was first isolated in 1983 at the Institute Pasteur in Paris.

Recently a new virus has been identified in West Africa, India and Srilanka. This virus, which is related to the virus first discovered acting in a similar way, with similar routes of transmission, is spreading to other parts of the world. The first AIDS virus is now called HIV-1 and the second, HIV2.

HIV selectively infects specific white blood cells (CD4) that are an essential part of the body's immune defence system. When the CD4 cells are destroyed, the infected person becomes susceptible to a range of opportunistic infectious diseases and cancers and the group of such conditions is called AIDS. HIV may also directly infect nerve cells and cause neurological disorders. HIV takes a long time to cause damage. HIV infection is presumed to be lifelong and the infected person is likely to remain infectious for life.

1.1 Structure

HIV is a member of the *retrovirus* family of viruses which has been known for many years to cause a number of different diseases in animals.

Like all retroviruses, HIV contains RNA in its core; the virus itself is surrounded by a protein and lipid envelope or "coat".

To replicate itself in human cells, the virus first needs to select cells to which it can attach itself; these are cells carrying a special "receptor" known as the CD4 antigen. This receptor occurs on cells in the body's *immune system*, the *helper T lymphocytes*, and on some *macrophages*. There is some evidence that other cells can support the growth of HIV, such as those in the lining of the bowel (bowel epithelium) and in the brain (microglia cells).

1.2 Replication

When the virus has made contact with a CD4-antigen-carrying cell, it sheds its lipid coat and injects its RNA into the human cell. The single-stranded RNA then makes a copy of itself with the aid of an *enzyme* called reverse transcriptase. This yields double-stranded *DNA*, which then inserts itself into the human cell DNA. Because HIV becomes part of the human cell's genetic material, infection of the cell is irreversible. Although it may be possible to develop a drug that suppresses the activity of the virus (thus keeping an infected person relatively healthy), there is no prospect of cure in the sense of eliminating the integrated viral DNA.

The viral DNA starts to instruct the human cell to produce viral components such as viral proteins and RNA – the two main components of HIV. The viral proteins migrate to the surface of the infected cell. Then, by a process known as budding, enormous numbers of new virus particles detach themselves from the infected host cell, and are taken away in the bloodstream to become attached to other cells carrying CD4 receptors.

Billions of virus are produced daily in the cells of the infected person.

The virus may remain dormant for months or even years, but if the infected cells are activated by the body's immune system in fighting another disease, HIV will begin to make copies of itself that will go on to infect more human cells.

Any other infectious disease, by activating the immune system, is therefore likely to lead to viral replication, but there is some evidence that a few common viral infections such as those caused by *herpes simplex virus* and *cytomegaloviral disease* can specifically enlarge the replication of HIV. Increased replication of the virus means that an infected person is more likely to develop full-blown AIDS because such replication leads to the progressive destruction of infected cells, thus destroying the body's immune system and decreasing its ability to fight off infection with other diseases. The advice given to those who are infected with HIV – to lead a healthy life-style – therefore has a firm scientific basis. (see "Practical Information for People with HIV Infection or Disease in Module V1 of this Guide").

If the infection is primarily in the brain, viral replication may cause it to deteriorate, which will often result in dementia associated with encephalopathy and possibly other opportunistic diseases.

Although the body's immune system does produce *antibodies* to the virus, they do not seem to be able to inactivate the virus. The virus in circulation therefore, is able to spread to other parts of the body and can also be transmitted to sexual partners, and passed on to others through infected blood, blood products, and other body fluids (semen, vaginal/cervical secretions), and from an infected mother to her child before, during or shortly after birth, and possibly also through breast milk.

1.3 Properties

HIV, like other viruses, is easily destroyed by boiling and steaming (autoclaving). The virus can be destroyed by various chemicals used in standard disinfectants – hypochlorite, glutaraldehyde and formaldehyde, normally recommended for hepatitis B virus – as well as alcohols, acetone, phenol, household bleach and several detergents.

However, the lipid envelope can protect the virus from dehydration. This means that contaminated fluid which has been allowed to dry may still contain infectious virus for hours or even days if kept at room temperature. It is important, therefore, to ensure that any surfaces or clinical instruments contaminated with body fluids are treated with effective disinfectants.

2. HIV INFECTION

2.1 Natural History of HIV Infection

People infected with HIV may take ten years before they develop AIDS as HIV takes a long time to do the damage. It is therefore important to distinguish between being infected with HIV and having AIDS. Those infected with HIV may suffer from disorders and develop signs which are suggestive of being infected with HIV. Acute HIV syndrome, associated with seroconversion can occur as early as few weeks after a person is infected. The person may be asymptomatic or develop 'flu like' symptoms and signs which are fever, lymphadenopathy (swelling of lymph glands), night sweats, skin rash and cough. The period before the development of an antibody response usually between 6-12 weeks is often referred to as the 'window period' when a person is *infectious* but not positive in HIV-antibody tests. Usually 3-5 years after the infection, generalized painless swelling of lymph glands develops

which persists for few months to many years. People with Persistent Generalized Lymphadenopathy (PGL) may also suffer from fever, night sweats, diarrhoea, loss of weight and infections such as thrush and herpes. The cluster of these signs and symptoms is called AIDS related complex or ARC. The diagnosis of having AIDS, the end stage of the disease, is demonstrated by the presence of one or more of the several opportunistic infections, cancers and other infections like pnuemonia, persistent diarrhoea, skin cancer called Kaposi's Sarcoma and infections of the nervous system leading to deterioration of intellectual capacity (dementia). It is essential to demonstrate the presence of HIV in the blood with the help of sensitive blood tests. The most widely used is the Enzyme Linked Immuno Sorbent Assay (ELISA) which detects the antibody generated in response to infection by HIV. Western Blot, a more expensive test, is no longer recommended for routine supplemental testing.

WHO has listed a few signs that help in provisional diagnosis of AIDS for public health purposes. The presence of two major signs with one minor sign (with presence of HIV antibodies) can be an indication of AIDS provided that other causes of depleted immunity like malnutrition etc. are ruled out. The major and minor signs are listed below:

Major Signs

- Weight loss greater than 10% of the body weight
- Fever for longer than one month
- Chronic diarrhoea for longer than one month (intermittent or consistent)

Minor signs

- Persistent cough for longer than one month
- General itchy dermatitis (skin irritation)
- Recurrent Herpes Zoster (Shingles)
- Oropharyngeal candidiasis (fungus infection in the mouth/throat)
- Chronic progressive and disseminated Herpes Simplex infections
- General Lymphadenopathy (swelling of lymph glands)

2.2 Neurological Manifestations

Neurological abnormalities, such as peripheral neuropathy and memory loss, in people with HIV infection are increasingly being reported. In some patients, they may be the initial manifestation of HIV infection and are often atypical in their presentation. The most frequent neurological disorder is a subacute encephalopathy characterized by progressive behavioural changes associated with dementia; it occurs in approximately one-third of people with late-stage HIV infection. Its onset is usually insidious, and cognitive dysfunction initially predominates. Common early signs include tremor, slowness, and aphasia. The course is usually progressive towards severe dementia. Mutism, incontinence, loss of vision, and paraplegia may develop in the terminal stages.

Other causes of neurological manifestations in people with HIV infection include cryptococcal meningitis, cerebral toxoplasmosis, lymphoma of the brain, and papovavirus and cytomegalovirus disease.

2.3 Manifestations in Infants and Children

A substantial proportion of infants who contract HIV infection from their mothers or from blood transfusions generally show symptoms by about 6-12 months of age. Children with AIDS survive, on

average, for about 18 months after signs first appear. Clinical manifestations include failure to thrive and to reach neurodevelopmental milestones, with the appearance of neurological manifestations in many HIV-infected infants. Weight loss, diarrhoea, oral and oesophageal candidiasis, pneumonia, and fever are common. However, these signs and symptoms also represent common background illnesses in the paediatric age group and make the clinical diagnosis of paediatric AIDS very difficult.

3. PROGRESSION FROM INFECTION TO AIDS

Initially it was thought that only a small proportion (5-10%) of HIV-infected persons would ultimately develop AIDS. Today, there is evidence that about 20% of those infected may develop AIDS within five years of becoming infected and about 50% within ten years. An increasing proportion will probably go on to develop AIDS after ten years, as people with HIV infection show progressive damage to their immune system over time.

4. CURE/VACCINE FOR AIDS

So far there is no cure for AIDS and a vaccine may be far away.

5. TUBERCULOSIS AND HIV

One of the several opportunistic organisms that can attack people with HIV infection is Mycobacterium tuberculosis, the organism that causes tuberculosis (TB). Though this organism is present in the bodies of one-third of the world's population, it generally remains dormant in healthy individuals because of their healthy immune system. In people infected with HIV, it is quick to gain an upper hand over the damaged immune system and spread to various parts of the body.

A parallel epidemic of TB following AIDS pandemic is already happening in many parts of the developing world. In some of the developed countries particularly in the United States of America, TB is resistant to multidrug therapy. In South-East Asia, where TB exists as a latent infection in nearly 40% of the population, the deadly duo of HIV and TB mean an additional drain on the meagre health resources. Effective treatment of TB is important.

6. TRANSMISSION

HIV has been isolated from the body fluids of infected persons, including saliva and tears: however, only blood, semen, vaginal secretions, and breast milk have been implicated in transmission. Detailed epidemiological studies throughout the world have documented only *three* modes of transmission: sexual, parenteral, and mother-to-fetus/infant.

6.1 Sexual Transmission

Worldwide, sexual intercourse is the most frequent mode of transmission of HIV. The virus can be transmitted from an infected person to his or her sex partner (man to woman, woman to man, and

man to man). Women are more at risk of getting the infection than men. During sexual intercourse (vaginal, anal, and possibly oral), damage to the linings of sexual organs such as vagina or rectum can facilitate transmission of HIV from the infected partner to the uninfected one by exchange of body fluids. It is easier for the virus to be transmitted if the uninfected partner is already suffering from some sexually transmitted disease, because in this case the lining is already damaged. Due to the high rate of sexual transmission of this virus, sexual behaviour is the prime focus for interrupting transmission.

6.2 Parenteral Transmission

Parenteral transmission occurs through the transfusion of infected blood or blood products, or the use of blood-contaminated needles, syringes, or other skin-piercing instruments. The risk of acquiring HIV infection is related to the size of the inoculum: recipients of unit of HIV-infected blood for transfusion have virtually a 100% probability of becoming infected.

Transmission through blood transfusion is a significant problem in countries where HIV infection is common and where nationwide HIV-antibody screening of blood donors has not yet been introduced. Transmission through HIV-contaminated needles and syringes is a particularly serious problem among injecting drug users, and where needles and syringes are not sterilized before reuse.

The risk of transmission in health care settings ie. from doctors/ nurses to patients or vice versa through needle pricks is very low – only 0.3%.

6.3 Perinatal Transmission

Transmission of HIV infection from a woman to her fetus/infant may occur before, during and after birth. The overall risk of HIV transmission from an HIV-infected woman to her fetus or infant *in utero* or during delivery is 15-39%.

Postnatal transmission through breast milk has been described in a small number of infants of mothers who acquired HIV infection after delivery.

In summary, the table given below shows the importance of transmission of HIV infection through each route of transmission discussed above. It is evident from the table, that sexual transmission is the commonest mode of spread in Asia.

HIV TRANSMISSION IN SOUTH-EAST ASIA, 1993

Route of Transmission	% of total
Sexual Intercourse	80 – 90
Blood Transfusion	3 – 15
Injecting Drug Use	5 – 10
Equipment/Needles	<0.1
Perinatal	<0.1

There is no evidence to indicate that HIV can be transmitted by the respiratory or gastrointestinal routes, or by casual person-to-person contact in the home or elsewhere.

There is no evidence to suggest that HIV can be transmitted through mosquitoes, food, water, toilets, swimming pools, sweat, tears, shared eating and drinking utensils, or other items such as telephones or second-hand clothing.

6.4 Who is at 'risk' of getting HIV Infection/AIDS?

Each and every one of us is at risk of getting HIV infection/AIDS. Certain practices carry high risk:

- Those who have sex with multiple partners especially when condoms are not used.
- Injecting drug users who share contaminated needles.

It is not who the individual is but rather what *an individual does that puts him/her at risk.*

Adolescents and youth are at a greater risk of getting infected because of their high risk behaviour.

People who receive HIV contaminated blood and blood products are also at risk.

7. PREVENTION OF HIV INFECTION

At present, prevention is the only cure for AIDS. In South-East Asia, where HIV epidemic is still in its early stages, prevention of HIV infection, in time, assumes paramount importance. Realizing the health and socio-economic impact of AIDS in the region, political commitment for AIDS has not been lacking.

AIDS prevention and control has three main objectives : to prevent HIV infection, to reduce the personal and social impact of HIV infection, and to mobilize and unify national and international efforts against AIDS. *Prevention is indisputably the most important objective.* No curative drug or a universally effective and affordable preventive vaccine is likely to be available in the foreseeable future.

7.1 Prevention of Sexual Transmission

It is important to have an information and education programme aimed at all men and women, to have facilities for detection and treatment of other STDs and to have an environment which would promote condom use and frank information exchange without stigmatization and discrimination against people known or suspected to have HIV/AIDS.

Several studies have demonstrated that use of condoms during sexual intercourse reduces the risk of transmitting or acquring infection with HIV as well as other STDs and that *proper and consistent condom use* can play an important role in AIDS prevention. Details of condom use are given in Module V in this Guide. Major challenges remain in the promotion of use of condoms in South-East Asia which include social, cultural and religious sensitivities, lack of access to condoms, and inability to talk frankly about condoms or sex. Social marketing of condoms is emerging as a successful approach for promoting condoms and enhancing availability for use among people with multiple sex partners and among youth. HIV transmission models suggest that if only 15% of sexually active urban men at highest risk of contracting HIV/AIDS – i.e. men who have multiple partners – adopted consistent condom use, then urban HIV prevalence would not increase.

Information to all persons to prevent sexual transmission of HIV

(a) Be aware that, if you have a mutually faithful relationship with your sexual partner, if you are both HIV seronegative, and if neither of you is exposed to contaminated blood, e.g., intravenous drugs or sharing needles, you are not at any risk of a sexually transmitted HIV infection.

(b) If you intend to have sexual intercourse and are *not in a mutually* faithful sexual relationship, be aware that your chance of acquiring HIV infection is influenced by the following main factors:

- The choice of your sexual partner(s)

  The risk of infection is directly related to the likelihood that your partner may be infected; for heterosexual and homosexual partners, this varies considerably according to the part of the world. However, there is no way by looking at someone to know if they are infected. Therefore, only through the use of condoms can you be sure that you are not exposing yourself to a risk of infection.

- The number of sexual partners

  The greater the number of partners with whom you have sexual intercourse, the greater the likelihood that you will encounter a partner with HIV infection. Therefore reduce the number of sexual partners to the greatest extent possible, and avoid having sex with people who have many sex partners.

- *Proper and consistent use of condoms* for from start to finish for *all* sexual penetrations (vaginal, oral and anal)

- The type of sexual behaviour practised

  Abstinence is the most sure way of preventing sexual transmission of HIV infection. However, for many people this is not acceptable or realistic. The use of condoms and other safer sexual practices such as those listed below are the only ways of decreasing the risk of becoming infected with HIV or transmitting HIV to a sexual partner:

  Restriction of sexual contact to activities that do not involve the sharing of semen, vaginal and cervical secretions, or blood (e.g., hugging, caressing) will eliminate the risk of acquiring HIV infection. Other "safer sex" practices include non-penetrative sex, masturbation, massage, kissing and hugging.

7.2 Prevention of Transmission via Blood

For prevention of HIV transmission through infected blood and blood products, the approaches that have proven effective include recruiting voluntary non-paid donors, screening donated blood for HIV and educating health care workers to reduce unnecessary transfusions. Preventing transmission at the health care setting rests on careful attention to infection control procedures including proper sterilization of equipments, proper adherence to procedures based on "Universal Precautions", and provision of necessary supplies and equipment. Preventing the blood-borne transmission among drug injectors should go hand-in-hand with efforts to prevent sexual transmission among them. These should include reducing demand for drugs, reducing the use of drugs by injection, and sterilizing the injecting equipment and needles by boiling or with bleach. Details of sterilization and use of bleach are given in Module V in this Guide.

The safety of blood and blood products, however, is an area where total control can be achieved by routine and mandatory screening of all blood samples for HIV. In Bhutan, Indonesia, Thailand, Maldives and Sri Lanka all donated blood is now screened for HIV, while in other countries of the South-East Asia Region, the proportion of blood screened is on the increase. Cost effective approaches in HIV testing are also being promoted, including testing of pooled sera, in populations where sero-prevalence of HIV is low. To avoid expensive tests, guidelines for alternative and cost effective testing techniques have been developed.

Recommendations to all people for prevention of parenteral transmission

(1) Avoid blood transfusion as far as possible. If a blood transfusion can not be avoided, then insist on having the blood tested for HIV prior to transfusion.

(2) Avoid injections for treatment when proper and equally effective oral medications are available.

(3) When the use of skin piercing instruments such as needles,syringes and blades cannot be avoided, insist on sterilized instruments.

(4) Do not share razor blades.

(5) Do not take drugs and if you cannot avoid taking drugs, do the following:

- Do not take injecting drugs.
- If you can not avoid taking injecting drugs, do not share needles and syringes or other injecting equipment.
- If sharing needles can not be avoided, then boil the needles and syringes and other injecting equipment or use bleach.

7.3 Prevention of Transmission from Mother-to-child

The best strategy for preventing transmission from mother to child is of course, to prevent the sexual transmission of HIV to women of reproductive age. Secondary prevention would depend on the avoidance of child-bearing by women who know or suspect that they are infected. Counselling and contraception services should made available to all women.

The prevention and control of AIDS, however, should not be seen as the sole responsibility of the health services. What is required is commitment at all levels – individual, the family, health personnel, media, etc.

8. SEXUALLY TRANSMITTED DISEASES (STDs)

8.1 What are STDs ?

STDs are Sexually Transmitted Diseases. Earlier, STDs used to be called venereal diseases. STDs are communicable diseases which are transmitted by an infected man/ woman to his/her partner during sexual intercourse. For this reason, they are called Sexually Transmitted Diseases. They are relatively easy to contract. STDs are serious and painful. Gonorrhea, herpes, chlamydia, syphilis and AIDS are the most common STDs.

A person becomes infected with STDs when he/she has:

- vaginal sexual intercourse, or
- anal sexual intercourse, or
- oral sex

with an infected person.

The vagina, penis, rectum and mouth are the sources from which the STD germs can invade the body.

8.2 STD Symptoms

Many STDs show early symptoms which disappear without treatment. But the germs remain in the body, causing damage to different organs. Some STDs give mild or no symptoms at all, particularly in women. One with an STD may look and feel healthy, but can still infect partners or unborn babies.

SOME SYMPTOMS OF STDs	
WOMEN	• Unusual discharge or foul smell from the vagina. • Pain in the lower abdomen – between the navel and sex organs. • Burning or itching around the vagina. • When having sex, pain deep in the vagina.
BOTH MEN & WOMEN	• Sores, bumps , blisters or rashes in or near the sex organs or mouth. • Burning pain while passing urine or having a bowel movement. • Swelling or redness in the throat. • Fever, chills and aches – like flu. • Swelling in the groin – the area around the sex organs.
MEN	• A drip or discharge from the penis.

There may be various complications due to STDs, if proper treatment is not given. They include:

- complications of pregnancy – congenital syphilis leading to stillbirth. Other STD infections may be responsible for other birth defects.
- complications in infants – infection with gonorrhoea causing blindness, other complications are conjunctivitis (an eye infection) and pneumonia.
- complications in others – infertility, hepatitis, dementia and cancer.

8.3 Prevention and Treatment of STDs

Abstinence is a fool-proof method of preventing STDs, but a really difficult one. The following guidelines can do much to prevent STDs :

- Avoid sex with partners who have genital rashes, redness, sores or discharges.
- Stay away from casual relationships.
- Reduce the number of your partners as much as possible.
- Use condoms.
- Urinate and wash the genital area after intercourse. This helps in avoiding some genital infections.
- Prevention of STDs would also reduce the risk of HIV transmission.

Early treatment is always desirable to prevent complications and further spread of infection. Upon suspicion of infection, the person needs to consult a health clinic or the family physician. Regular check-ups are also recommended if safer sex is not practised, or as soon as any sign of an STD is noticed. Most STDs can be cured if correct treatment is given. It should be remembered that early diagnosis and treatment of STDs would prevent HIV transmission.

Epidemiological data worldwide as well as in South-East Asia show that the major mode of HIV transmission is through sexual intercourse and that HIV is primarily a sexually transmitted disease. The relationship between STDs and AIDS is twofold : (1) STDs are a marker for high risk behaviour; the same high risk behaviour predisposing for STDs also predisposes for HIV infection (i.e., unprotected sexual intercourse with multiple partners); and (2) STDs appear to serve as an important risk factor facilitating the transmission and acquisition of HIV infection. HIV transmission is easily spread in a person who has genital ulcers caused by STDs. STDs which do not cause ulcers are also implicated. Some studies have shown that women having HIV infection are more likely to have had infections which do not cause ulcers. Moreover, internal sores or inflammation often pass unnoticed in a woman, and inflammation alone also increases the risk of HIV transmission.

Thus the control of STDs contributes significantly to a reduction in HIV transmission.

SUMMARY

The first cases of AIDS were seen in the United States in 1981 but the virus responsible for the disease was isolated in 1983. It is now known as the human immunodeficiency virus (HIV). HIV infects the CD4 white blood cells; these are an essential part of the body's immune system so that, when they are destroyed, the infected person becomes susceptible to a range of opportunistic infections and cancers. HIV is a retrovirus, i.e., its core consists of RNA. When this RNA is injected into a human cell, an enzyme called reverse transcriptase converts it into DNA, which is then inserted into the cell DNA. Replication takes place when the infected cells are activated in fighting another disease. Although antibodies to HIV are produced in the human body, they do not inactivate it.

Acute HIV syndrome, associated with seroconversion can occur as early as few weeks after a person is infected. The person may be asymptomatic or develop 'flu like' symptoms and signs. The 'window period' is when a person is infectious but not positive in HIV – antibody tests. Usually 3–5 years after the infection, generalized painless swelling of lymph glands develops which persists for few months to many years. The diagnosis of having AIDS is demonstrated by the presence of one or more of the several opportunistic infections, cancers and other infections like pnuemonia, persistent diarrhoea, skin cancer called Kaposi's Sarcoma, infections of the nervous system leading to deterioration of intellectual capacity (dementia). It is essential to demonstrate the presence of HIV in the blood with the help of sensitive blood tests. Current evidence suggests that about 20% of those infected with HIV may go on to develop full-blown AIDS within five years and about 50% within ten years. Sexual intercourse is the most frequent mode of transmission of HIV; parenteral transmission also occurs through the transfusion of infected blood or the use of blood-contaminated skin-piercing instruments; while perinatal transmission refers to the passing on of HIV infection from mother to child before, during or shortly after birth. Children can contract HIV infection from their mothers, sometimes from breast-feeding.

Due to the absence of a preventive vaccine or curative drug, prevention is the only cure. Prevention via the sexual route involves reducing number of multiple or unknown sexual partners, practising safer sex options and usage of condoms for all sexual penetration activities. Ensuring screening of blood and blood products, and proper sterilization of all surgical equipment/needles reduce transmission-risks by the blood route. Thirdly, prevention of infection to childbearing women or avoidance of pregnancy by infected women are the prevention options for perinatal transmission.

STDs refer to communicable, sexually transmitted diseases which have a direct relationship to HIV infection. STDs are an indicator of high-risk sexual behaviour and increase the chances of HIV transmission particularly among those with genital ulcers. Thus, early and effective treatment of STDs becomes crucial to prevention of HIV transmission.

MODULE 2

HIV COUNSELLING: ITS NATURE AND PURPOSE

MODULE 2

HIV COUNSELLING: ITS NATURE AND PURPOSE

Objective: To enable the trainees to understand the principles of HIV counselling and the need for such services.

Time to complete Module: 2 hours 15 minutes.

SUMMARY OF ACTIVITIES

(1) Role play & Brainstorming : What is counselling?
(2) Small group activity : HIV counselling as distinct from other forms of helping.
(3) Review Questions.

Activity 1: ROLE PLAY & BRAINSTORMING: WHAT IS COUNSELLING? (20 minutes)

This activity is designed to introduce the trainees to the concept of counselling. The trainer begins by inviting three group members to volunteer for a role play. He/she gives them a brief description of their roles (two members are the clients and one plays the counsellor) and instructs them to enact the role play spontaneously for 10 minutes.

After the role play, the trainer asks the full group to brainstorm on what they observed and understood about what is counselling. Make brief notes of the responses on the flip chart. Allow 10 minutes for the brainstorming. At the end, put up Overhead #1 giving a general definition of counselling.

Activity 2: SMALL GROUP ACTIVITY: HIV COUNSELLING AS DISTINCT FROM OTHER FORMS OF HELPING (1 hour 30 minutes)

This activity is designed to familiarize trainees with the concept of HIV counselling, and its distinction from other activities. Allow up to one-and-a-half hours for this session.

Divide group into sub-groups of four people. Give each group the following prepared chart on a piece of flip chart size paper and ask them to brainstorm and complete the vacant cells of the matrix using the whole sheet of paper. An alternative or even an addition to writing down responses in words, is for the sub-groups to draw them in picture form or even to act them out as small role plays so they can see visually the differences between the various activities.

Type of Helping Activity	"Consists Of" Or Main Features	Strengths (+) and Weaknesses (–)
Giving Advice		
Offering Information		
Showing Sympathy		
Listening		
Health Education		
HIV Counselling		

As well as completing the chart, ask each group to offer their own definition of HIV counselling.

After thirty minutes, put up the charts on a wall and ask one person from each sub-group to take the whole group through the contents of the charts. Ask that person also to offer the group's definition of HIV counselling and write that down on a blackboard or whiteboard or flip chart. How do these compare with each other?

After each group has reported back, look at the HIV counselling definitions and list on the flip chart essential features from the various groups' definitions. How does this relate to the WHO definition? (see Supplementary Reading).

Activity 3: REVIEW QUESTIONS (25 minutes)

Trainees fill in their responses on the worksheet of review questions, individually. Allow 10 minutes. The trainer then ends this Module – session with a general discussion/sharing of various members' responses to each of the three questions in the worksheet for 15 minutes.

WORKSHEET: *REVIEW QUESTIONS*

(1) What can counsellors do to reduce the stress of those infected with HIV?

_____

_____

_____

_____

_____

(2) How is counselling different from health education?

(a) _____

(b) _____

(c) _____

(3) How can counsellors help individuals to cope?

_____

_____

_____

ROLE PLAY: *For Activity 1*

Neena and Shyam are a married couple who have a one year old child. They have been married for two years. Shyam works as an engineer while Neena is a schoolteacher. Neena had to take some months leave during her first pregnancy. Now, Shyam is keen to have a second child but Neena feels this is not the right time for another child. They come to a counsellor for help.

OVERHEAD # 1: *For Activity 1*

DEFINITION OF COUNSELLING

"Counselling is a helping process where one person, explicitly and purposefully, gives his/her time, attention and skills to assist a client to explore their situation, identify and act upon solutions within the limitations of their given environment."

Supplementary Reading

HIV COUNSELLING: ITS NATURE AND PURPOSE

HIV COUNSELLING: ITS NATURE AND PURPOSE

In counselling, two people who are in no way related to each other meet to resolve a crisis, solve a problem, or make decisions involving highly personal and intimate matters and behaviour. The counsellor's emotional detachment in assessing the client's case is extremely important, although people who know nothing of counselling may misinterpret it at first as lack of interest or unfriendliness. There is, however, a continuous gradation between detachment and closeness, within which the counsellor must find the correct balance; this is important in promoting the well-being and problem solving skills of the client.

The client may know nothing about counselling or what it involves. Talking to a stranger about personal matters may be frightening, intimidating or culturally prohibited. The counsellor should begin, therefore, by finding out what the client knows about counselling and expects of the counsellor. If necessary, the counsellor should explain the process briefly, illustrating it with examples, discuss the client's fears about it, and then listen to the client's own account of the problem. This account will be subjective and perhaps inaccurate, but the client should be satisfied that the counsellor is giving full attention to the matter. This is the basis of trust. It is important to understand that counselling is about helping people, and that, as all people are different, there can be no universal or predetermined method of counselling. However, the need for prevention of infection and the commitment to providing support to people already affected by HIV are present in all cultures and contexts.

HIV/AIDS counselling has two general objectives: (1) to provide psychosocial *support* to those already affected; and (2) to *prevent* HIV infection by changing life styles and life style/ behaviour. In order to achieve these objectives, counselling seeks to enhance self-determination, boost self-confidence, and improve family and community relationships and quality of life. HIV/AIDS counselling therefore also means providing support to families and loved ones, so that they, in turn, can help to encourage and care for people with HIV infection.

Prevention and support are mutually complementary. In HIV counselling, prevention efforts that are not accompanied by some type of support are unlikely to be effective. The acceptance of prevention messages is always improved when these messages are made personally relevant to individual needs and life-styles. The way in which those messages are provided in a counselling context should also encourage a feeling of trust and understanding that make behaviour modification attractive and sustainable.

Counselling is concerned with individuals, couples, families and groups. Counselling provides psychosocial support and strengthens the sense of individual responsibility needed if people are to build on new information and modify their life-styles. *This involves helping people to define for themselves the nature of the problems they are facing and then make realistic decisions about what they can do to reduce the impact of these problems on themselves and their family and friends. Therefore, helping people to achieve the confidence to make life-style changes is an integral part of the counselling relationship.*

Counselling as a process can:

(1) ensure passing-on of correct information;

(2) provide support at times of crisis;

(3) encourage change when change is needed for the prevention or control of infection;

(4) help clients focus and identify for themselves their immediate and long-term needs;

(5) propose realistic action suitably adapted to the different clients and circumstances;

(6) assist clients to accept and act on information on health and well-being; and

(7) help clients to be well-informed and appreciate the technical, social, ethical and legal implications of HIV testing.

The techniques used in counselling may vary from country to country, and perhaps also within countries, depending on the background of the people being counselled and the type of health or social services locally available. Effective counselling need not follow any set pattern or approach. It should certainly not be restricted to a clinic or a structured doctor-patient situation. The most successful counselling often takes place outside the context of formal relationships.

Counselling nevertheless involves much more than a single or occasional informal discussion. The need for continued support and help with problem-solving is a common feature of most HIV-related situations and should be a key aspect of most counselling relationships.

1. WHO IS HIV/AIDS COUNSELLING FOR?

In the context of HIV/AIDS, counselling is recommended for the following:

- Persons already identified as having AIDS or being infected with HIV, and their families.
- Those being tested for HIV (pre-and post-testing.)
- Those seeking help because of past or current risk behaviour and planning their future.
- Those not seeking help but who practise high risk behaviour

With these priorities in mind, the types of situations in which counselling is of value, and people seek care, might include :

- people with AIDS or other disease related to their HIV infection;
- people experiencing difficulties with employment, housing, finances, family, etc. as a result of HIV infection;
- people considering being tested for HIV;
- people who have been tested for HIV (whether or not they are infected);
- the family and friends of people who are infected with HIV;
- people worried that they might have become infected with HIV;
- health workers and other professionals who come into regular contact with people infected with HIV;
- people who choose not to be tested despite past or present risk behaviour;
- people who are unaware of the risks of HIV infection involved in specific behaviours they have, or are, engaged in.

2. WHERE CAN IT BE PROVIDED?

HIV/AIDS counselling can take place in any setting where there is, or could be, a discussion about HIV/AIDS. Such settings include wards in hospitals, centres for sexually transmitted diseases, antenatal and postpartum clinics, family planning clinics, blood donation centres and sites, drug de-addiction centres, prisons, community health centres, schools, churches, outpatient clinics, and all health outreach or community-based programmes. There will inevitably be other types of settings that should be considered for the purpose.

However, the counsellor should pay attention to the specific setting in which the client or family is seen. Is it at home? In a clinic/office? In a hospital room? In a public place? Each of these settings will call for different responses from the counsellor. Each will influence responses from those being interviewed. A supportive, helpful relationship cannot develop if the counsellor does not acknowledge both *the gravity of the problem* and *the context* within which discussions about it take place. For example, trying to ask questions about sensitive personal topics in a crowded clinic waiting-room obviously calls for an approach quite different from asking the same questions in a private place. Attention to context is important in any form of counselling, but is particularly important in counselling with relation to HIV infection because of the severe stress and stigma associated with the condition.

3. WHO SHOULD PROVIDE IT?

In addition to doctors, nurses, psychologists, psychotherapists and social workers, other people can readily be encouraged and trained to provide counselling support. Counsellors need not be professional health-care providers. Teachers, health educators, laboratory personnel, religious and community leaders, youth group workers, traditional healers, and members of self-help groups can undertake both preventive and supportive counselling.

4. WHY IS IT NECESSARY?

Being diagnosed as having, recognizing the possibility of, or suspecting the existence of HIV infection or AIDS all have profound emotional, social, behavioural, and medical consequences. The type of personal and social adjustment required in the context of HIV infection often has implications for family life, for sexual and social relations, for work and education, for spiritual needs, for legal status, and for civil rights. Adjustment to HIV infection involves constant stress management and adaptation. It is a dynamic, evolutionary, and lifelong process that makes new and changing demands on individuals, their families and the communities in which they live.

Most people are limited, or feel that they are limited, in what they can do and in what changes they can make in their lives. Whether these limitations are real or imagined, or whether they are past or present, they all have to be taken into account and dealt with if behaviour modification is to be successful and sustained.

During the course of HIV infection, a broad range of physical needs and problems are likely to be experienced. These are not necessarily constant, and will progressively become more serious and difficult to handle. They call for increased and different resources, both for those who are HIV-infected and for the people looking after them.

The changing nature of these needs imposes a variety of psychological and emotional strains on individuals and those closest to them, which may threaten identity, independence, privacy, and social status. They can also involve fears of loneliness, of dying and death, of guilt and anger. Dealing with HIV disease also imposes direct and indirect financial costs, particularly when economic productivity is affected by illness; much of the stress experienced by people infected with HIV may reflect underlying anxieties about economic independence and family obligations.

Counselling must therefore take into account not only the most immediate social and medical environment of clients, but also their social relationships and attitudes and beliefs about HIV/AIDS. Counselling must also ensure that factual education and information are provided in a way that is truly *relevant* to the day-to-day life of the person concerned. It must take into account such things as the sexual needs and history of the patient, occupation, education, aspirations, and hope, together with what will be needed to inspire new and perhaps different approaches to safer sex and responsible social relationships.

Counselling the family, lovers, friends, employers, or colleagues of people with HIV must include providing up-to-date, technically correct information. It should also take into account the life-style of the person with HIV and seek to explore the opportunities for, and constraints on, changes in behaviour and constructive adaptation to HIV infection.

If counselling is to be effective, it must first of all be seen as acceptable. Its acceptability will always be improved if it clearly takes into account the nature of the many social relationships, commitments, and obligations most individuals have. Each of these relationships may have the potential for motivation and support.

In summary, counselling people about HIV infection is important because:

- infection with HIV is lifelong;
- a diagnosis of HIV infection can create enormous psychological pressures and anxieties that can delay constructive change or worsen illness, especially as the HIV epidemic has given rise to fear, misunderstanding and discrimination;
- behavioral change can prevent a person acquiring HIV infection or transmitting it to others.

5. MAIN FUNCTIONS OF COUNSELLING

Counselling has two main functions : the provision of social and psychological support to those affected by HIV and the *prevention* of HIV infection and its transmission to other people.

5.1 Psychosocial Support

People diagnosed as having HIV infection and HIV-related illness, including AIDS, and those close to them are confronted by a host of problems that call for emotional and/or practical support. Anxiety about having spread infection, physical isolation, hospitalization, discrimination within the community or family, loss of housing, interruption of education, financial problems, the physical effects of illness, disease progression, loss of relationships, bereavement, anger, loneliness, and depression are all concerns that may have to be managed.

These problems may be periodic, both for the person with HIV/AIDS and for those providing care for them. The fact that they are not always constant and not always predictable produces physical

and emotional stress. Counselling can be particularly helpful in identifying the circumstances under which these concerns are likely to be present and in helping the person plan how to best deal with them in a proactive fashion. Where this is not possible, counselling can help the person react to these problems as and when they arise.

It is important to remember that counselling incorporates a process of *empowerment* for the person with HIV. *Living with HIV infection or disease does not mean living despite HIV; through counselling, the personal strength and resources to face and manage such concerns can be identified and mobilized, so that living with HIV may include periods of constructive enrichment quite independent of the crisis of infection or illness.* Counselling may not be required for this purpose, but where people cannot see beyond their infection, it can assist persons with HIV to normalize aspects of their lives that they may otherwise overlook.

Counselling should help those affected by HIV to live fully and productively by enabling them to resume (or assume) authority over their own lives and decision-making. Problems can often be placed in a new light, allowing a more creative approach to problem-solving and decision-making. Counsellors may often find themselves in the role of "patient advocate", generating a therapeutic strength in individuals, families, or communities by their support.

Enabling people to remain active in their work, in their education, in their families, and among friends helps to reduce dependence on health and social services and can also reduce the likelihood of psychological problems.

5.2 Prevention

There are five main steps in situations where prevention of HIV infection is the primary goal of the counselling interaction. These are:

(1) determining whether the behaviour of an individual or group of individuals involves a high risk of HIV infection;

(2) working with the people concerned so that they understand and acknowledge the risks associated with their behaviour;

(3) defining with them how their life, attitudes/values and self-image is linked to these behaviours;

(4) helping individuals to define their potential for attitude shifts, behaviour modification and change; and

(5) working with individuals to introduce and sustain the modified behaviour.

Within any culture or social group, high-risk behaviours are likely to be influenced by a variety of factors. Peer-group pressure to perform in a particular way, financial pressures, cultural beliefs about what is acceptable and expected, opportunity to innovate, and lack of knowledge about the risks involved may all play a role, depending on the person and situation concerned.

Counselling requires a substantial input of health education, but health education messages need to be made personally relevant and in the context of achievable goals. They also need to be presented in the context of detailed and sympathetic discussion. Counselling seeks above all to encourage individuals and groups to make choices about personal life-styles and responsibilities. In order to be

effective, consistently accessible support for the individual or group being counselled must be available. Where there is no feeling of dialogue or exchange between the counsellor and the client, and no feeling of genuine support, the essence of the preventive message can often be lost.

(1) Primary prevention

Counselling for primary prevention is needed by people who are at risk of HIV infection but are not known to be infected. Some of them may already *recognize* that they are at risk; others will be *unaware* of the risk involved in their behaviour. Counselling in primary prevention thus focuses on highlighting and discussing behaviour that presents a risk of HIV infection, and reviewing ways of managing individual change that will lead to their giving up of high-risk behaviour as outlined above. In any society, a variety of individuals and groups may be at risk. Commercial sex workers and their clients, other men and women with many sex partners, men who have homosexual relationships, people with haemophilia, and people who inject drugs deserve special attention. In addition, however, military personnel, truck drivers, and migrant workers who spend long periods of time away from home, and adolescents may all be pressured by their everyday circumstances to engage in risky behaviour. Each of them represents a different challenge with regard to how and where they can be reached. Bars, clubs, hospitals, drug treatment centres, military bases, schools, youth clubs, and sports clubs can all provide opportunities for counselling or at least for informing people about the availability of counselling.

(2) Secondary prevention

For persons known or considered likely to be HIV-infected, counselling should emphasize the implications of HIV infection and the ways in which transmission can be avoided. This should be done in a context of support and understanding, focusing on the need for personal responsibility for the health and welfare of those with whom individuals may have intimate sexual contact.

In this context, referral by health centres, testing facilities, hospitals and other institutions or organizations becomes especially important. The staff at these places therefore need to know, and inform people with HIV, where counselling is available. They also need to be able to help the client find a counselling service that is physically and socially accessible and most likely to be acceptable to the person concerned.

Outreach for counselling to prevent secondary transmission may need to be just as innovative as primary prevention programmes. Some people diagnosed as HIV-infected are likely to move from place to place in search of friends, support, and care, and in an effort to deal emotionally with the fear of AIDS. They may be reluctant to participate in counselling or any other follow-up activity unless steps are taken to reach them and help them appreciate the benefits of counselling.

The question of the sexual transmission of HIV needs to be addressed in counselling for secondary prevention. The importance of adopting practices that eliminate or minimize the possibility of infecting sex partners must be emphasized. Condom use, low-risk sexual practices, alternative ways of seeking gratification, and celibacy will need to be discussed. Similarly, the need to inform current or previous partners about the possibility that *they* have been infected may need to be considered, and different ways of reaching these people reviewed.

In considering the prevention of transmission through blood or blood products, counselling needs to stress the importance of not donating blood and of not sharing syringes, needles or other skin-piercing equipment. Drug injectors often have or select friends who share the same behaviour. Pressure from friends to continue high-risk practices is likely and has to be appropriately planned for. Similarly,

the difficulties in reaching and working with drug injectors, who are afraid of prosecution or of rejection by family and acquaintances who do not know about their drug behaviour, will have to be addressed.

Perinatal transmission may also be an important concern. In the case of women who are already pregnant, the possibility of interrupting the pregnancy or the desire to do so will have to be dealt with, taking into account all the many cultural, familial, emotional and medical factors that can influence such a decision. Prevention of future pregnancies should also be discussed.

6. CONTENT OF COUNSELLING

As already pointed out, the main functions of counselling are the provision of support and information to those affected by HIV, AIDS or related diseases. In addition counsellors may be called on to provide information and support to those seeking to prevent infection or re-infection. Certain basic information on HIV/AIDS will have to be provided in all such counselling. Information must often be repeated to clients over the course of different sessions.

HIV/AIDS counselling should therefore include discussion of the following:

- the primary need to prevent infection and re-infection;
- basic information about HIV infection and associated diseases, and means of transmission;
- assessment of the level of risk of HIV infection;
- review of possible sources of a client's infection;
- specific information on risk reduction by changing risk behaviour, e.g., through protected or safer sex;
- exploration of cultural and value obstacles to changing behaviour or adopting safer sexual practices;
- information about what testing can and cannot do, and assessment of the consequences of having the HIV-antibody test;
- follow-up guidance after testing has been done;
- how to tell others that one is HIV-infected; and
- handling hostility, fear and feelings about having HIV infection or being diagnosed as having AIDS.

When a person is diagnosed with HIV, counselling must also include:

- supporting the process of anticipatory grief;
- planning for continued involvement of the client in self-care;
- establishing or re-establishing a support network to provide physical and emotional care during the course of the disease;
- exploring ways of taking care of survivors; and
- accepting fear of death and continuing to provide emotional support.

7. COUNSELLING AND RESISTANCE TO CHANGE

Counselling is one of the principal means of helping people understand why they resist changing their behaviour, and the counsellor may need to explore and explain reasons repeatedly and in various ways.

Knowledge alone is not sufficient to bring about or sustain change in behaviour. Even when people understand how HIV infection is spread, they may resist changing their behaviour and using the resources – including counselling – which are available to them. They may see no point in doing so, or they may fear losing face – a man may feel it unmanly to use a condom or a woman may not wish to offend her partner by asking him to do so, or to change behaviour might go against traditional or religious beliefs. Frequently, the habits and kinds of behaviour to be changed will have been pleasurable to the person, or have an important symbolic meaning.

Simply informing people is not enough; it does not affect factors in the environment that may contribute to, or reinforce risk behaviour.

> "When responsibility for change is not shared (individual-social) changes that occur are more likely to be temporary because of lack of reinforcement in the physical and social environment. For example, many educational and skill development approaches assume that individuals lack knowledge or skills, and attempt to provide what is lacking in the individual. However, if the broad environment does not lend support for the use of the knowledge, then the likelihood of the knowledge being used is reduced. Additionally, even if the knowledge is used, the change may be insufficient to overcome the problem. While education, provision of knowledge, and skill development may all be necessary, they are not sufficient to stimulate and maintain change. They are important as part of the basis of health promotion; however, too often they are also the end point." An example is the commercial sex worker who is knowledgeable about the use of condoms to protect herself from HIV infection during sexual intercourse. She may not be in a position to refuse a client who does not wear a condom as she has no support from the brothel authorities. Therefore, inspite of the knowledge due to lack of social support the sex worker cannot put to use the knowledge she has acquired.

To promote and sustain the behavioural changes needed to prevent HIV transmission, the counsellor needs to work intensively not only with infected or sick persons but also with their families and other people who matter to them. Moreover, the counsellor will have to be sensitive to other people and to attitudes in the social environment which may inhibit behavioural change or actively promote and support risk behaviour. The people who should be included in the counselling process will vary in each individual situation and will depend to a certain extent on who the HIV-infected person *chooses* to be included. Family members, loved ones, friends, and colleagues in the workplace – all may be involved in the counselling process. The degree to which they are involved will depend in part on the needs of the HIV-infected person but will be influenced as well by the need of the individuals themselves to be included. It is essential for the counsellor to maintain a view of the HIV-infected person not as an isolated individual but as a person within a larger social framework. In each instance that framework will need to be defined and will thus determine who will be included in the counselling process.

After learning that they are HIV-positive, people may have strong feelings. Most will be shocked, some people may enter a stage of denial. Many, especially if they feel well, will refuse to accept that they have the disease or that they could harm themselves or other people. HIV infected persons may feel angry and blame themselves or others; some may even want to take revenge by infecting others. Some may enter into a bargain thinking that they will be cured if they performed a good act. Most will feel lonely and will be afraid of losing their jobs, people rejecting their friendship, their families deserting them, pain, death etc. Each of the situations mentioned above need counselling. What is likely to move people is concern for spouses or partners and for their children's well-being. Fear alone may not be a sufficient motivation, but the counsellor must consistently and patiently keep them well aware of the risks and support their efforts to change their behaviours.

8. COUNSELLING AND HEALTH EDUCATION

Psychosocial counselling in relation to HIV infection *and* health education of the public are the primary ways of: (1) reducing resistance to behavioural change; (2) helping people adjust to the need to change behaviour; (3) assisting individuals, families, and communities to use social, medical, spiritual and economic support systems; and (4) reinforcing healthy behaviour which may already exist.

Counselling thus complements health education, but serves a different purpose for the many people who may not believe that they themselves are directly threatened, who find it hard to change risk behaviour, or who are unable to apply general information to their own specific circumstances. Counselling is essential to help such people to:

(1) understand the consequences to themselves and others of their risk behaviour;

(2) define their potential for changing risk behaviour to protect both their own health and the well-being of others; and

(3) find and use the personal and social resources necessary for starting and maintaining behavioural change or managing illness.

Education is an important tool for counsellors. A counsellor teaches constantly, giving new information, separating fact from myth, and informing clients about available resources.

The counsellor both guides and educates, whether in helping a client determine how to avoid infection, deciding whether or not to take a test, or explaining how HIV infection is transmitted. *Counselling is therefore geared to motivating people to interpret information, incorporate it, and act on it.* The aim is toward helping people cope with their stress and fears regarding their potential or actual infection with HIV.

Health education and counselling both : aim at changing risk behaviour; use two-way interaction and rely on communication skills. However, beyond just education, which is emotionally neutral, counselling involves strong emotional overtones. The role of the counsellor then augments the coping capacity of the individual and family to deal with the emotional impact of HIV infection.

Finally, counsellors must keep up with current knowledge and combine this knowledge with the skills of listening, supporting and guiding.

SUMMARY

HIV/AIDS counselling is aimed at providing psychosocial support and preventing HIV infection. Psychosocial support is necessary because a diagnosis of HIV infection confronts people with a host of emotional and/or practical problems. Counselling is of vital importance in overcoming resistance to making the changes in behaviour that are necessary if risk is to be avoided and transmission prevented. Counselling in the context of prevention can take the form of primary prevention, intended for people at risk but not known to be infected, and secondary prevention, where clients are known or thought likely to be infected. Primary prevention focuses on risk behaviour, while the main emphasis in secondary prevention is on preventing transmission. Counselling implies education but, unlike health education, is directed towards the specific needs arising from HIV infection. It also involves communication; however, it differs from casual conversation in that the information exchanged and obtained is specific, focused, and serves a purpose.

MODULE 3

VALUES AND ATTITUDES OF A GOOD COUNSELLOR

MODULE 3

VALUES AND ATTITUDES OF A GOOD COUNSELLOR

Objective: To enable the trainees to appreciate the need to be non-judgmental, and explore their own attitudes and values which may come in the way of counselling.

Time to complete the Module: 2 hours 25 minutes.

SUMMARY OF ACTIVITIES

(1) Pair work: Exploring attitudes.
(2) Group discussion: Values continuum.
(3) Presentation: Need to be non-judgemental.
(4) Individual work: Listing of words.
(5) Summarizing.
(6) Review Questions.

Activity 1: PAIR WORK: EXPLORING ATTITUDES (30 minutes)

This activity is designed for the participants to become more aware of their own personal values and attitudes. This will also give them a chance to listen to different opinions and values of their colleagues.

Trainees complete the "fill in the blanks" exercise in worksheet 1. Each trainee finds a partner and discusses why he/she agrees or disagrees with the statement. Allow 25 minutes for this activity.

The trainer sums up by discussing the following issues with the group: (5 minutes)

- Why are these called "controversial" statements?
- Have you heard of such statements being made by people? Which ones are most frequently stated?
- Did you feel comfortable discussing your views with your partner?
- Were you surprised when your partner disagreed with you?
- Did you change any of your views after listening to your colleagues?

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Activity 2: GROUP DISCUSSION: VALUES CONTINUUM (45 minutes)

Ask participants to sit in a circle in groups of no more than 10 or 12. Give each participant one of the following cards. Instruct them not to disclose to others what is on their particular card:

oral sex
marriage
anal sex
family planning
vaginal sex
homosexuality
incest
masturbation
extra-marital sex
bisexuality
sex before marriage
using addictive drugs
having more than one sexual partner at a time

In the middle of the floor place two cards some distance apart: one reading ***Acceptable to me***, the other ***Unacceptable to me***. Explain to participants that these cards represent a continuum which ranges from totally acceptable to totally unacceptable. Participants will take it in turns to read out the word or words on their card, say how they personally feel about that particular topic and then place the cards somewhere in the continuum where they feel it belongs. When everyone has placed the card somewhere in the continuum, discussion is opened up for others to express their opinions on the placements of various cards. After listening to the views and opinions of other participants, explain that they each now have the opportunity to move the card from where they placed to another in the continuum if they so wished.

It is *not* the purpose of this activity to achieve agreement in terms of responses to these different topics; instead it is to explore the differences in values which will exist in any group.

In plenary, discuss :

- How did it feel to express your own values here in this group?
- How did it feel to listen to others express their values?
- Were you surprised by anything?

Allow 45 minutes for this activity.

Activity 3: PRESENTATION: NEED TO BE NON-JUDGEMENTAL (15 minutes)

Using the experience of the exercise conducted as Activity 2, the trainer explains how being judgemental adversely affects counselling. He/she gives the following examples :

Statement by Counsellee : "I went to a prostitute last night. Do you think I could have caught AIDS?"

Counsellor's Reaction : "What can you expect if you indulge in this bad habit?"

Statement by Counsellee	:	"I am going to have an arranged marriage next month, but my parents and future husband do not know that I am having an affair with a boy in my college. I don't know what to do"!
Counsellor's Reaction	:	"I am ashamed of you. Shall I tell your parents?"
Statement by Counsellee	:	"For the past one year I am taking drugs. Now, I hear that people who take drugs get AIDS. Is that true?"
Counsellor's Reaction	:	"Of course, it is true. You should never take drugs."

Now ask the participants to volunteer to respond in a non-judgemental way to each of the 3 statements given above. They may either verbalize or write their responses. Ask a few of them to call out their responses for each statement and acknowledge the ones which are non-judgemental and supportive.

Give 15 minutes for this presentation.

Activity 4: INDIVIDUAL WORK: LISTING OF WORDS (30 minutes)

The worksheet #2 for this activity has several words/phrases along the left margin. The trainees will be asked to put down two words that come spontaneously to his/her mind in response to the trigger words. Encourage trainees to use words that reflect an *emotional* response to each trigger word rather than merely provide alternate words/synonyms to mean the same thing. Even if the exercise is being conducted in English, the words may be expressed in the local language if found more expressive.

Trainees will be asked to do this exercise fast, allowing only five minutes for this part of the activity.

The trainer then takes all the worksheets, and one-by-one asks participants to take any one sheet at random, read out the responses to any one trigger word and discuss whether the listed words are primarily positive or negative. All participants must get the opportunity to read out and discuss the responses to at least one trigger word and the whole list must be covered.

The trainer takes note of the responses and uses his/her observations to summarize with the group how different words are perceived and reacted to emotionally. Allow 30 minutes for this activity.

Activity 5: SUMMARIZING (10 minutes)

The trainer highlights (preferably through use of overhead transparencies) the points brought out in this module, that people from different backgrounds have different values which influence attitudes towards HIV infection and AIDS. There is thus need for counsellors to explore their own attitudes and values that may come in the way of counselling. It is important to be non-judgemental.

Activity 6: REVIEW QUESTIONS (15 minutes)

Allow 10 minutes to the trainees to fill the worksheet 3. Trainer to discuss the likely answers with the trainees.

WORKSHEET 1

CONTROVERSIAL STATEMENTS: "FILL IN THE BLANKS" EXERCISE

In the blanks fill in an (A) for agree and (D) for disagree.

1. _____ Women with HIV infection should not have children.
2. _____ People with AIDS should be allowed to continue work.
3. _____ AIDS is mainly a problem of people with immoral behaviour.
4. _____ Men who have sex with men indulge in abnormal sexual behaviour.
5. _____ People with HIV infection should be isolated to prevent further transmission.
6. _____ It is a collective responsibility to care for people with HIV infection.
7. _____ I would feel uncomfortable inviting someone with HIV infection into my house.
8. _____ Surgeons should screen all patients for HIV infection before surgery.
9. _____ I would feel uncomfortable discussing sexuality with a person of the opposite sex.
10. _____ Injecting drug users should compulsorily be tested for HIV.
11. _____ It is alright for men to have sex before marriage.
12. _____ School children should not be educated about safer sex.
13. _____ Women should never have extra-marital sexual relations.
14. _____ All professional blood donors should be jailed.
15. _____ It is difficult for male counsellors to talk to women clients about condom use.

WORKSHEET 2

LISTING OF WORDS

List two words that come to your mind spontaneously when you think of the following words. As far as possible, list words that reflect your emotional response to the given word instead of a mere translation or definition of the word. For example, two words for "sex" may be: 1. Fun; 2. Immoral.

Sex Worker	1.	2.
Professional Blood Donor	1.	2.
Pregnancy	1.	2.
Injecting Drug Users	1.	2.
Teenager	1.	2.
Condom	1.	2.
S.T.D.	1.	2.
Homosexual	1.	2.
Masturbation	1.	2.
Wife	1.	2.
Boy Friend	1.	2.
AIDS	1.	2.

WORKSHEET 3

REVIEW QUESTIONS

(1) Why is it important for a counsellor to examine and understand his/her own attitudes?

_____

_____

_____

(2) Why is it necessary to be aware of cultural influences on counselling?

_____

_____

_____

(3) Why is confidentiality important in counselling?

_____

_____

_____

(4) Is it possible to maintain confidentiality of a test result in your workplace?

_____

_____

_____

(5) What are the barriers within *you* that you have discovered in this session, which need to be overcome to enable you to be non-judgemental as a counsellor?

_____

_____

_____

_____

Supplementary Reading

VALUES AND ATTITUDES OF A GOOD COUNSELLOR

VALUES AND ATTITUDES OF A GOOD COUNSELLOR

1. COUNSELLOR VALUES AND ATTITUDES

People are influenced by the culture within which they live, develop and mature. Every culture has certain kinds of behaviour, ceremonies, rites of passage and points of view that are *preferred* above all others. These are called *values*. Some values are practically universal – preserving the lives of innocent people, for example - but the values which guide and direct day-to-day behaviour are usually specific to the culture in which they evolved.

The counsellor must understand and accept that people from different backgrounds have different values, and that these values influence attitudes towards HIV infection or AIDS. Values determine the degree to which a person asks for help, or attempts to handle a problem alone. They also determine how people view health, illness, and death.

Counsellors will have their own values, attitudes and beliefs but have to work with clients who may have quite different ones. Fear and prejudice against people with AIDS causes stigma, discrimination, hostility and oppression, and may even be stronger than the values which underlie the humane care of the sick. Counsellors themselves share their culture's prejudices, and must therefore examine and recognize their own prejudices and values. Competent counsellors do not have to like all their clients, but should be keenly aware of their own feelings, opinions, attitudes and prejudices. They must learn to recognise when they are not communicating clearly, or are distracted by the background or appearance of their clients, or are being influenced by bias rather than facts.

Counsellors must never allow their own personal values or prejudices to influence their counselling. If a serious conflict seems likely, the client should, if possible, be transferred to another counsellor. If this is not possible, the counsellor should consult a supervisor or colleague for help in resolving the difficulty.

Some institutions may benefit from operating a formal policy of reducing or eliminating prejudice or discrimination, implemented with the help of staff training at all levels, and supervision or staff support groups.

Counsellors must explore and reflect on their own feelings and prejudices which can interfere with the objective assessment of clients or, in the case of unremitting work with distressed and dying clients, can cause severe depression and inability to relate to other people. They will also need to decide how ready they themselves are to discuss sensitive topics and to what extent their own inhibitions and attitudes will complicate the task.

The kinds of questions which counsellors might ask themselves are:

- What are my *own feelings* about people whose behaviour has placed them at risk of infection? About people with HIV infection or AIDS? Am I afraid, critical, overwhelmed ...?
- In view of the ways in which the infection is sometimes contracted, can I treat certain persons as fellow humans, or will I see them as being at fault and immoral?

- Which sexual practices would be most difficult to talk about, given my own personal and cultural values?
- What everyday/slang words would I use, or never use, to explain risk practices or behaviour, especially to clients who differ from me racially, culturally or sexually, or are much younger or older?
- Can I maintain my own values of individual worth and dignity for everyone, even if my client's cultural background and way of life are very different from mine?
- How would I explain the need to discuss behaviour that is seen as strange or deviant in a particular society or culture?
- In this culture, to what extent am I ready to let clients do what they decide to do and take responsibility for their own care? Will I involve others in decisions if it is the accepted thing to do, or always try to be in control?
- How much do I want to influence, control or dominate other people?
- Are there some kinds of people or types of behaviour of which I disapprove so strongly that I probably could not counsel those concerned competently?

Counselling regarding sensitive and deeply personal topics requires the counsellor to:

(1) *Feel secure and at ease* when enquiring about intimate matters that are rarely discussed openly, and be *able to convince* clients of the need to talk about taboo topics in order to prevent transmission of infection.

(2) *Focus the discussion* on specific practices and behaviour. The detail needed (e.g. number of partners, frequency of sharing needles) may embarass the client, and even the counsellor, who must nevertheless find culturally acceptable ways of dealing with these sensitive topics (e.g. instructing clients in "safer" or "protected" sex).

To support their clients emotionally and help them to change their behaviour, counsellors should pay attention to certain important values and attitudes which keep counselling focused and directed, as discussed below:

Maintenance of Confidentiality. This is essential in any kind of counselling. The counsellor must assure a client that his/her sharing personal or intimate feelings and events will be respected and kept confidential. This is very important in building trust in the counselling process.

Positive regard. Counsellors must view clients as individuals with problems and respect them without judging or condemning their past behaviour. They should not add to the self-blame or guilt which characterizes many clients.

Acceptance. Counsellors need to appreciate the stress caused by the fear of being infected or the need to change behaviour. They must accept the resulting emotions and reactions of clients and their close associates, even including resistance and hostility to the counsellor.

People with HIV infection and/or disease (including AIDS) should always be encouraged to feel that they are fully accepted by the counsellor, irrespective of their life-style, sexual preference, and socioeconomic, ethnic or religious background. While responses to their needs should be technically sound, counsellors should, at the same time, be sensitive to their personal circumstances and not be affected by subjective feelings about a person's background.

Empathy. Empathy is more than sympathy, which is generally not very useful in counselling, although it may be expressed as a statement of support (e.g., "I am sorry that you are having to go through this pain.")

Empathy involves trying to place oneself in another's situation. The counsellor cannot truly say "I know how you feel," because that is impossible with HIV infection.

The counsellor can demonstrate empathy by changing the counselling approach to make it culturally more acceptable to a person, or modifying the mode of communication to make it more understandable. Empathy is very often conveyed not in words, but through non-verbal communication, e.g., by nodding the head, changing position, or using gestures understood within the culture to mean "I am listening and responding to you."

Self-determination. Ideally, people take responsibility for their own conduct and how they behave when they are ill, but the degree to which they can do so is strongly influenced by culture and tradition. Some cultures are fatalistic about illness, for example, and have little place for self-determination. In other cultures, people are expected to do as they are told by someone above them. Still others attach great importance to self-determination.

So far as cultural norms allow, the counsellor should encourage self-determined behaviour, but appreciate that people who are frightened or ill may not feel disposed to exercise self-determination. Rather, they will be disposed to look to others for support and decisions. The counsellor should always try to counter this inclination and support the client's autonomy with information and guidance on sound decisions, even at times of severe stress.

Understanding grief, mourning and loss. HIV-infected people or their families often grieve for, and mourn prematurely their anticipated loss. The counsellor needs to focus during his/her training and experience on what loss means, become familiar with the various cultural ways of expressing grief, and become skilled in discussing with clients, and helping them have recourse to, their spiritual sources of comfort and support.

Mobilizing resources. The counsellor should not try to provide everything the client needs, but rather be fully aware of, and able to use competently the *formal* and *informal* resources on which people can call. Formal resources include medical care services, income or food supplements, and counselling. Informal resources include families and friends, religious groups, civic clubs, and peer-support groups. The counsellor can also encourage the development of new social resources if the need arises.

2. CULTURE AND TRADITION

Persuading people that they should change their behaviour and motivating them to do so are major counselling tasks. They will do so, or even consider doing so, only if the counsellor appreciates the cultural importance of the behaviour to be changed.

"Culture" can be defined as the habits, expectations, behaviour, rituals, values and beliefs that human groups develop over time. Through culture, people learn acceptable behaviour, what is right and wrong. It determines or influences social status and the use of language. Culture is a product of the interaction of people, ideas and the physical environment.

Human beings interpret the world and their place in it according to their culture. It determines their feelings and beliefs about health and illness, about caring for the infirm, and about death and loss. Traditions, handed down from one generation to another, may be particularly important at times of transition (puberty or marriage rituals) or stress (illness or death).

Culture and tradition therefore influence how people interpret, explain, and respond to HIV infection and AIDS. Counsellors must examine their own beliefs, so as to be able to listen without prejudice and

without censure to people from different backgrounds and cultures. They must first and foremost learn about, and respect, the culture and traditions of others, and not forget that culture, and therefore attitudes and behaviour, varies within countries, regions and groups.

2.1 The Culturally – Sensitive Counsellor

A counsellor may sometimes unknowingly behave or speak in ways which a client from another culture interprets as unusual, rude or even threatening. Then the client may become silent and seem to withdraw from the session. When this occurs, the counsellor should comment on it, encourage an explanation, and change or adapt the counselling method.

It is largely in its use of words, or language, that counselling is adapted to culture. Language both expresses and shapes thought. Communication can take the form of speech (verbal) or of body language (non-verbal). These methods of communication are influenced by culture, which determines the form that they take and how they are accepted.

The counsellor should acknowledge differences so that they do not hinder or block the development of the counselling relationship. The counsellor must be sufficiently secure to admit unfamiliarity with a client's culture and to know how to question the client in order to decide how to conform to the client's cultural norms.

2.2 Cultural Attitudes Towards Illness and HIV/AIDS

The counsellor needs to be able to recognize and respect cultural definitions. One culture may see illness as punishment, another as fate. What one culture considers a normal response to illness, another may find irrational or strange. Counsellors must very quickly explore their clients' and the prevailing beliefs about illness and, in particular, HIV infection, by asking questions such as :

- What do people believe causes illness; how do they explain illness and death?
- AIDS is attributed to what causes – biological (a virus) or metaphysical (punishment from God, witchcraft, etc.)? To what extent is ill health in general seen as accidental, due to environmental factors, or as a consequence of moral transgressions? Are there any locally perceived risk factors, such as migration to a large town or, for example, "walking in the bush at night"? Do people understand the concept of contagion through contact with another person? Are drug injectors seen as being at risk? Is there any association with particular occupations, such as midwifery, or with animals?
- What do they call this illness? Does it have a local name? Is there any understanding of the difference between HIV infection and clinically expressed AIDS?
- How is AIDS recognized? What are the symptoms and how are they distinguished from other manifestations of the opportunistic infections that are common in AIDS? What is the likely course and outcome of the disease? Are there any social and behavioural manifestations of the illness?
- Do people have any ideas on prevention or ways of protecting themselves and their families? (Biomedical measures and those mentioned in health education campaigns should be mentioned only after local ideas have been explored). This will include the extent to which people see themselves and their families to be at risk and the steps they are taking to reduce that risk.
- What do people think and say about HIV-infected people?
- What is expected of people with regard to caring for the sick? Is the family expected to provide care?
- Are certain conditions, especially HIV infection and AIDS, considered to be so evil or dangerous that the affected person is abandoned or shunned?

- What forms of treatment do they believe in?
- Where, and from whom, would a person be most likely to seek treatment? Why?
- Would anyone other than the infected person be involved in the treatment? Why? How?

The counsellor's efforts to motivate behavioural change must take into account the client's and family's belief systems.

Having clarified how the disease is regarded and explained, the counsellor must then take care to use readily comprehensible words, images and symbols, as well as to avoid those that are not acceptable. If the counselling methods are not adapted to the client's culture and belief systems, counselling will fail.

2.3 Cultural Attitudes Towards Health and Healers

Counsellors must take into account and be clear about:

- what a culture sees as right and wrong;
- whether people are blamed for their illnesses;
- how much guidance, advice or help people want or need in order to talk about or manage illness, given the rules and common practices in their culture;
- how people feel about discussing intimate matters with people who are strangers to them, of the opposite sex, or from different backgrounds;
- whether or not counselling about sexual matters would be more successful if the counsellor is of the same sex as the client;
- what people regard as a safe and proper conversational distance. (In some cultures people stand very close to one another while talking, and look one another in the eyes. In others, people stand well apart, and turn slightly away from one another. A counsellor who uses the "close" style will experience difficulty in connecting with a person from a "distance" culture);
- how people interpret silences and certain kinds of gesture. (In some places, a shrug may indicate "I don't know"; in another, "I don't care");
- slang or colloquial expressions for illness, HIV infection, AIDS and related diseases;
- who are recognized as helpers and healers;
- what treatment is given locally to AIDS patients. To what extent are health service facilities used. Is there a role for centres such as hospices. Who is responsible for the care of AIDS patients in the home and how does this affect domestic roles and economic production. To what extent is the local community involved, including religious leaders and traditional healers;
- how actively should helpers or healers direct or guide the patient. Is the person expected to passively accept everything ordered by someone in authority, or play an active part in care, and in decisions;
- how direct and outspoken can a healer or counsellor be;
- what words or gestures should not be used because they are rude or indecent;
- whether there are matters that people will not discuss without continuous reassurance, permission or encouragement from the helper or healer.

The counsellor must take care to use words in the sense in which the client uses them, and to check carefully with the client if there is any doubt.

2.4 Culturally Determined Rituals for Death and Cultural Sources for Healing

Different cultures have different rites for terminal illnesses, death and bereavement. The counsellor must ensure that those concerned can observe their customary rites and get in touch with those who perform

them. The counsellor should be acquainted with the use of ritual observances for spiritual comfort or protection, and should know who administers or performs the rites, or who can be approached in spiritual matters.

In some cultures, spiritual or traditional healers may not know how HIV infection is transmitted. They might even harm an infected person with their remedies and cause the infection to continue to be transmitted. The counsellor should make every effort to establish contact with them and explain to them the modes of HIV transmission, the nature of HIV transmission and AIDS so that they can modify their practices.

Often, the counsellor has to help clients and their families deal with major changes in behaviour and living arrangements, disablement or disfigurement, or impending death. They will react to HIV infection or the possibility of it, or to clinical AIDS, in various ways – fear of abandonment, or of pain, disfigurement, and helplessness. How these fears are expressed will be partly determined by the culture.

The counsellor can help them to discover and use acceptable ways of expressing anger, guilt, fear or sadness. If it is not culturally acceptable to display emotion, the counsellor might help them find some relief by talking privately about their feelings. In places where it is easier to discuss certain topics with strangers than with family members, the counsellor may help to find or establish a group of similarly affected people and train them to listen to, and support one another emotionally.

2.5 Cultural Attitudes Towards Prevention

The counsellor who appreciates the influence of tradition and culture can establish with a worried person or with a HIV-infected individual and family:

- a common definition of the problem;
- an acceptable way of explaining it; and
- a culturally acceptable way of handling it.

Because HIV infection is transmitted sexually, cultural and personal attitudes towards sexuality and other prevention options are extremely influential. The counsellor must realize, too, that some people may hesitate for cultural, religious or moral reasons to consider the use of condoms, or any form of contraception.

It is particularly difficult to change culturally and traditionally sanctioned behaviour, such as male extramarital sexual relationships. The justification for change in this context must be compelling, e.g., the protection of children from infection, or from deprivation or destitution which would be a result of the breadwinner's death at an early age.

Facts alone will often not be enough to change cultural attitudes, which must then be accepted and the client helped to find other means of protection – for example, by weighing the emotional costs and consequences of sexual abstinence against those of a morally proscribed practice such as using condoms.

The attitudes of others, including those of the public authorities, towards prevention and care, must also be considered, since these attitudes can determine whether the client will change behaviour and cooperate in treatment. Fear of social stigma may lead to denial, resignation or fear of abandonment.

Maintaining sensitivity to cultural issues and differences can be very demanding. The counsellor must try and understand the sort of life another person has led, which includes knowing the ideas, ideals and symbols that define the person's identity and means of coping with misfortune.

Counselling can involve discussing behaviour or ideas that may be taboo in the counsellor's culture; it can go beyond tolerating differences to a genuine appreciation of the critical importance *to the client* of something to which the counsellor may be very hostile. Even a very experienced counsellor will sometimes feel shocked or offended. Counselling requires self-discipline, as well as self-knowledge, familiarity with various cultures and beliefs, and openness to different views and interpretations.

3. SOCIAL NORMS & PRACTICES INFLUENCING SEXUALITY AND HIV TRANSMISSION

Information about social norms and cultural influences on sexual behaviour can be obtained by asking the following questions:

(1) What are the main ethical and religious principles in the society related to kinship, marriage, celibacy, widowhood and divorce? How do these apply to sexual unions, either before, during and after, or between marriages, in relation to the sexual life cycles of individuals?

(2) What information is available on topics such as coital frequency and periods of abstinence, e.g., during menstruation, pregnancy and breast-feeding?

(3) What forms of contraception are used in different types of sexual relationship and through the sexual life cycle, with particular reference to condoms?

(4) How are migration and other forms of travel associated with, and influenced by patterns of sexual behaviour?

(5) To what extent do people engage in sex in exchange for money, material or other resources and what relationships of this type exist? What are the characteristics of people who engage in these relationships? To what degree are they socially acceptable?

(6) Do homosexual and bisexual relations occur? If so, among which groups and to what extent do the individuals concerned interact sexually with others in the population?

(7) What are the main forms of penetrative and non-penetrative sex practiced, among which groups, and to what extent are they related to each other? Are there any sexual practices which may be especially conducive to the spread of HIV infection (e.g., anal intercourse)?

(8) To what extent are sexual matters discussed between spouses, or within families, and formally and informally in schools and the media?

SUMMARY

People from different backgrounds have different values, which influence attitudes towards HIV infection and AIDS. Counsellors also have their own values and share their culture's prejudices, but must not allow them to influence their counselling. Important values and attitudes include positive regard, acceptance and empathy. Culture and tradition influence the way in which people respond to HIV infection and AIDS, and counsellors must respect those of others. They must therefore explore the prevailing beliefs about illness and, in particular, HIV infection, and their efforts to motivate behavioural change must take these belief systems into account. They must help clients and their families to discover culturally acceptable ways of expressing emotions such as anger, guilt, fear or sadness. Because HIV infection is transmitted sexually, cultural attitudes towards sex and sexuality are extremely important in prevention; it may be difficult to change culturally sanctioned behaviour and therefore it is necessary to find other forms of protection.

MODULE 4

EFFECTIVE COUNSELLING TECHNIQUES

MODULE 4

EFFECTIVE COUNSELLING TECHNIQUES

Objectives: (a) To enable the trainees to understand the attributes of an effective counsellor.

(b) To enable the trainees to understand and practice the useful techniques and barriers to success in counselling.

Time to complete the Module: 3 hours 45 minutes.

SUMMARY OF ACTIVITIES

(1) Brainstorming: Qualities of an effective counsellor.
(2) Exercises: Micro-counselling skills.
(3) Presentation: Essential stages of counselling.
(4) Role plays: Counselling skills.
(5) Brainstorming: Hinder – and – Help factors.
(6) Review questions.

Activity 1: BRAINSTORMING EXERCISE: QUALITIES OF AN EFFECTIVE COUNSELLOR (15 minutes)

This activity is designed to enable trainees to identify the personal attributes and attitudes that are necessary for becoming an effective counsellor. Ask the trainees to brainstorm on what they think are the qualities of a good counsellor. The trainer helps in listing down the points on a flip chart while the discussion is on. The trainer should refer to the "Guide for Trainer" sheet given after the Review Questions to ensure that the essential qualities are covered. Allow 15 minutes for this activity.

Activity 2: EXERCISES: MICRO-COUNSELLING SKILLS (2 hours)

This activity is a practical, hands-on exercise where an understanding and demonstration of basic counselling skills will be imparted to the trainees. Four skills will be taught and practised with a time allocation of 20-25 minutes for each skill. The format for the activity is as follows:

- Introduction of the skill to the full group
- practice of the same in triads
- re-assembling for feed back and explanation of the skill as a full group
- back to the triads and so on.

(1) Begin by naming and introducing the 4 micro-counselling skills that will be practised in this session. Use Overhead#1 as a Guide at this point as well as during the description of each skill, later on.

(2) Next, explain the procedure to be used for the practice sessions. Divide the group into triads of 3 people. Each person will get a chance to play the role of counsellor, client and observer interchangeably. Describe the three roles to the group using Overhead #2. Each "skill-practice" session will consist of the following time allocation:

> Client and counsellor talk for 5 minutes in each triad. When the trainer calls time after 5 minutes, the observer gives his/her feedback (primarily commenting about the person playing role of "counsellor", followed by comments by the client about how the session *felt* for him/her. The full group will then re-assemble and the trainer invites general comments from the clients, counsellors and observers (few from each role) regarding how the particular skill being practised came out in their triads (for e.g.: Was it difficult or easy? Did it seem helpful and useful? How?).

(3) Next, read out and explain the "Rules for Effective Feedback", Overhead#3, so as to ensure that the comments given by the observer and client after each 5-minute "micro-counselling skill" role play are constructive and helpful to the person playing "counsellor" in terms of his/her learning.

(4) After clarifying any doubts or apprehensions that may be expressed, begin the practice sessions by describing the first skill, i.e. "Active Attending/Listening" with the help of Overhead#1. Break the group into their triads so they may work on it for 10 minutes, followed by 10 minutes of full-group discussion. Follow the same format for the other 3 skills, i.e.: Reflection of Feeling, Questioning and Paraphrasing & Interpretation.

(5) End the session by emphasizing the fact that these were the beginning, basic micro-counselling skills, which need to be practised regularly to be fully effective and there are other, more advanced skills, too, which are mentioned in the Supplementary Reading section.

Activity 3: PRESENTATION: ESSENTIAL STAGES OF COUNSELLING (15 minutes)

This presentation will help the participants to put into focus the real-life stages and *processes* of conducting counselling. The trainer gives a brief presentation on how the counselling relationship is initiated between a counsellor and client and the various stages that follow. He/she displays Overhead#4 to illustrate these stages. It needs to be emphasized that time and attention should be given to each stage in the order they appear, so that the client understands what are the goals and focus of each stage. This helps strengthen the client-counsellor relationship and makes the client feel supported.

Activity 4: ROLE PLAYS: COUNSELLING SKILLS (45 minutes)

The trainer introduces the concept of role play and its importance as a learning experience and skill development.

Four volunteers are sought from the group: two to play counsellors and the other two to be the clients while the rest of the group observes. Trainees role play 2 different scenarios, demonstrating the counselling skills and qualities which they have just learned. Hand a paper with the role play scenario to only the client to read. Give him/her 5 minutes to read and prepare for it – the group should *not* know the scenario. This will allow for genuine responses and true practice of the skills by the counsellor. Do this for both the role plays.

Each scenario lasts about 20 minutes, broken up as follows: 5-7 minutes of role play of the situation, 5 minutes for de-brief between the counsellor and client, and 10 minutes for groups' comments on the positive elements and weak spots they observed as well as the trainer's feedback. At the end, the trainer ends the session by commenting on the skills demonstrated in the two role plays and their impact on the counselling interaction. Allow 45 minutes for this activity.

Activity 5: BRAINSTORMING: HELP AND HINDER FACTORS (15 minutes)

This brainstorming calls attention to the elements that aid counselling and those that hinder the interaction, including personal attitudes, qualities and communication issues. In a sense, it reviews the essential aspects of counselling already learnt by the participants and allows for an expression of their internal understanding of counselling.

The trainer makes two columns on a flip chart or board with the two headings: "Factors That Help" and "Factors That Hinder". He/she then asks the trainees to brainstorm about those features or elements that would help the counselling process in making it more effective and lists them on the flip chart/board. He/she then invites the group to also list out those things or factors that would hinder or negatively affect the counselling relationship. The trainer reviews the list and then uses the Guide below to add any essential features that may have been left out. Allow 15 minutes for this activity.

Guide for Trainer

Factors That Help	Factors That Hinder
- Encourage *independent* decision-making. - Ask client whatever you don't understand. - Maintain confidentiality. - Refer case when beyond your skills or get a consultation. - Encourage client to get family and friends' support.	- Pass moral judgements on client's behaviour or feelings. - Take on more than you can handle. - Stereotype the client. - Increase *or* slow the pace of the process according to *your* needs. - Make generalizations and minimize the issue or compare it to others' situations/problems. - Ask questions for your interest/needs rather than those of the client.

Activity 6: REVIEW QUESTIONS (15 minutes)

The trainees complete the worksheet. Allow 10 minutes for this exercise. Trainer asks 2-3 participants to share and discuss their answers with the group, and clarifies any misconceptions or vague elements for each question in a summary form.

WORKSHEET: *Review Questions*

(1) **List 5 attributes of a good counsellor.**

(a) _____

(b) _____

(c) _____

(d) _____

(e) _____

(2) **List 5 characteristics of good counselling.**

(a) _____

(b) _____

(c) _____

(d) _____

(e) _____

(3) **Which skill of the 4 micro-counselling skills was the easiest for *you* to practice during the sessions?**

_____

(4) **Which skill of the 4 micro-counselling skills was the most difficult for *you* to practice during the sessions?**

_____

GUIDE FOR TRAINER : *For Activity 1*

During the brainstorming session, the trainer should try to elicit as many of the following qualities as possible from the trainees and at the end, go over the following list and add any qualities that have not been mentioned by the participants.

QUALITIES OF AN EFFECTIVE COUNSELLOR

(1) Positive regard or respect for people.
(2) Open, non judgemental and high level of acceptance.
(3) Caring and empathetic.
(4) Self-aware and self-disciplined.
(5) Knowledgable/informed about subject and awareness of resources available within the community.
(6) Culturally sensitive.
(7) Patient and a good listener.
(8) Ability to maintain confidentiality.
(9) Objective and having clarity.

ROLE PLAY SCENARIOS: *For Activity 4*

Role Play # 1

Hari is a 22-year old college student. He has been on drugs with a group of his college mates for the past 2-3 years and they regularly inject heroin at parties. He heard about AIDS on the radio and decided to go for an HIV test. The result was positive. He has just received the result and is feeling very depressed and suicidal. He does not know whom to turn to among his friends and family. He comes to a counsellor for help.

Role Play # 2

Meena, a 30-year old woman, has been married to Dev for 7 years and they have a 5-year old son. Dev works with an electronics company and travels out of town quite often. He recently confessed to Meena that he had tested HIV positive and it was due to the occasional one-night stands with call-girls during his out-of-town trips. Upon his insistence, Meena went to have her blood tested for HIV antibodies. She has also tested positive and is very upset about it. She is feeling a sense of anger and betrayal towards Dev. Before talking to Dev, she comes to a counsellor to find out more about HIV/AIDS *and* decide what to do next.

OVERHEAD#1 : ***For Activity 2***

BASIC MICRO-COUNSELLING SKILLS

Active Attending/listening

Indicating or showing that you are listening, hearing and paying attention to the client by words, expression and gestures (i.e. verbal and non-verbal communication). Active listening involves patience. It means long discussions from the client and brief, calm responses from the counsellor. E.g.: Relaxed posture, occasional nodding, no note-taking or interrupting while client is talking, encouraging the client to tell you more.

Reflection of Feeling

Picking up the client's feelings and letting him/her know you have understood how and what he/she is feeling. Focus is on the emotions. E.g.: *Client* – "I really wanted to meet my sister yesterday but I had too much housework to do and so could not go." *Counsellor* – "It seems you felt *sad* when you could not meet your sister yesterday."

Questioning

Asking questions to understand clearly the client's problems or worries *and* to help client go deeper into his/her own awareness or insight. Questioning is centred around the concerns of the client rather than around the curiosity of the counsellor. Questions need to be open-ended which allow for more explaining/elaborating by client rather than multiple-choice or "Yes-No" questions. Substitute "Why?" or "How" in a question with some other word. E.g.: *Counsellor* – "*How* did you react to your employer scolding you?" *rather than* "Did you leave the room when your employer scolded you?"

Paraphrasing and Interpretation

Paraphrasing – Repeating in one's own words what the client has said to show one's understanding. Saying it in a few words so that it gives a summary or the essence of the client's words. E.g.: *Counsellor* – "You got worried when you got home yesterday and your wife was not back from work." (After client has talked *in detail* of coming home and not finding his wife there).

Interpretation – Giving back to the client the *core* or basic issue he/she is talking *around* or *hinting* at. Picking up what the client is feeling but not saying. This skill involves going to a slightly deeper level of the issue to point out feelings or meanings which are just below the surface of the client's awareness. Check with the client if one's interpretation is correct. E.g. : *Counsellor* – "You have just explained to me that you think courtesy and respect are the two most important human values. That gives me the feeling that you would be very upset if someone was rude to you. Is that true?"

OVERHEAD#2 : *For Activity 2*

Role of Client

Please think of a situation or event or relationship that made you feel happy (for first skill of Listening), sad or scared (for the second skill of Reflection of Feeling), worried or hurt (for the third skill of Questioning), and depressed or intensely angry (for the fourth skill). It needs to be something that you have gone through in the past or are dealing with right now. Share this with your "counsellor" during the 5 minutes you play the role of a "client" and respond spontaneously to whatever the counsellor says or does. While giving feedback, please let the counsellor know how effective his/her communication was in helping you or making you feel better.

Role of Counsellor

Become the counsellor for the person playing client for 5 minutes while he/she shares his/her concern or situation with you. Practise using the skill you are learning in that micro-session as often as you can. Also, give the client your undivided attention and try to avoid noticing the observer who is in your triad. Listen carefully to the feedback you get from the client and observer and think of how you can incorporate it in your work.

Role of Observer

Carefully and silently observe the interaction between the client and counsellor during their 5-minute "session" Pay careful attention to the usage of the skill-in-question by the counsellor. Also observe to what extent the counsellor can help and support the client in understanding his/her situation. Please remain strictly apart from the interaction, like a fly on the wall, seeing but not seen. Do not get drawn into the session even if the client or counsellor looks at you or turns to you. During feedback time, please try to give comments following the "Rules for Effective Feedback"about things that were helpful and those that could have been done more effectively.

OVERHEAD#3 : *For Activity 2*

Rules for Effective Feedback

Begin your sentences with "I" as these are only *your* subjective feelings and views. Someone else may feel differently about the same issue. So, make "I feel", "I think" statements.

Give *positive* comments/feedback *first* and then the weaknesses/mistakes you saw – the idea is to help the person learn more and improve, not to demoralize him/her.

Also, try to offer alternatives or suggestions (things you feel would have been more effective) when talking about the mistakes or weak spots.

Use simple words and short sentences.

Do not interrupt or side-talk during the client-counsellor interaction.

Give *specific* comments about the *actions* or behaviour of the person – not about the whole person or his/her traits. The comments should be about things the person can do something about or work on, not *who* he/she is.

OVERHEAD#4 : *For Activity 3*

ESSENTIAL STAGES OF COUNSELLING

Stage One – **Forming Rapport and Gaining the Client's Trust.**

Stage Two – **Definition and Understanding of Roles, Boundaries and Needs.**

Explaining and making clear to the client the roles and boundaries of the counselling relationship. Establishing and clarifying the client's needs and goals – with the most urgent and important ones to be addressed first, followed by more general, long-term issues.

Stage Three – **Process of Ongoing, Supportive Counselling.**

Encouraging the client to begin a consideration of possible options and assessing possible solutions/decisions and their implications. Enabling the client to take charge and move towards change.

Stage Four – **Closure or Ending the Counselling Relationship.**

Supplementary Reading

EFFECTIVE COUNSELLING TECHNIQUES

EFFECTIVE COUNSELLING TECHNIQUES

1. QUALITIES OF A GOOD COUNSELLOR

Counselling is both an art and a science, a "science" because of its underlying principles, an "art" because of the blend of the counsellor's personality, technique and skill. People who just start training as counsellors often look anxiously for the *techniques* to help them work effectively with clients. Techniques are very helpful, but they are secondary to the *ability to form a helping* relationship. This is established and developed by the attitudes and qualities of the counsellor. The essential qualities of a good counsellor are listed below:

(1) Positive regard or respect for people.
(2) Open, non judgemental and high level of acceptance.
(3) Caring and empathetic.
(4) Self-aware and self-disciplined.
(5) Knowledgable/informed about subject and awareness of resources available within the community.
(6) Culturally sensitive.
(7) Patient and a good listener.
(8) Ability to maintain confidentiality.
(9) Objective and having clarity.

2. COUNSELLING SKILLS

Communication is the counsellor's principal tool. Communication skills are employed to ensure that client and counsellor correctly interpret each other's messages and comments, and their responses are consistently appropriate and helpful. Because counselling almost always involves communicating about sensitive issues, and differs from advising, counsellors must develop the skills of *Listening, Supporting, Guiding, Confronting, Assessing and Maintaining Self-awareness*. Effective counsellors adapt their counselling style to the characteristics of the person or family being counselled. Good communication also depends on careful observation.

Typically, the counselling of HIV-infected persons takes place at times of stress, when they need support, information, and an opportunity to express and discuss their feelings. The trained counsellor becomes skilled in imparting information, encouraging productive expression of feelings, asking about sensitive or taboo topics or kinds of behaviour, and finding ways to induce clients and their family/friends to change behaviour. This calls for a range of skills, including:

(1) ***Active Attending or Listening***. The counsellor indicates by words, expression and posture/gesture that very careful attention is being given to what is being said, clarifies uncertainties by interrupting and asking questions, and then helps the client resume the narrative. By utilising good attending behaviour to enhance the client's self-respect and to establish a safe atmosphere, the counsellor facilitates free expression of whatever is in the client's mind.

(2) ***Reflection of Feeling.*** The counsellor must recognize feelings such as anger, sadness, and fear in a direct, unemotional way, indicating both verbally and non-verbally: "Your feelings are very strong, and I accept them, and I accept you". The focus is on the emotions of the client and his/her subjective experiences in coping with the situation.

(3) ***Questioning.*** The counsellor always tries hard to use questions to make communications clear so that both the problem and the solutions are clear. The communication itself (for example, "Do you mean...?"), or the facts (for example, "No, HIV infection is not transmitted by eating out of the same dishes") can be clarified. The counsellor asks questions in order to bring to awareness all the dimensions of the problem and help the client to go deeper and face the core issue underlying his/her fears or concerns.

(4) ***Paraphrasing.*** Many people can tell they are being understood accurately if the counsellor repeats what they have said in different words – for example, "You seem to be saying that you are afraid your family is not going to take care of you". The client might then agree with the interpretation. If not, the counsellor can clarify the matter. When utilizing this technique, the counsellor attempts to feed back to the client the essence or content of what the client has just said.

(5) ***Interpretation.*** Often people will avoid focusing on the real problem and talk around the issue. Interpretation goes beyond what is explicitly expressed to the feelings and meanings only implied by the client's statements and which are somewhat below the surface of the client's awareness. It removes or *redefines* from a different point of view or brings out more clearly, feelings which are at the edge of awareness. The counsellor helps to establish what is relevant, emphasizing the important points - for example, "Of all the things you talked about today, it seems to me you are most concerned about...".

(6) ***Repeating.*** At times of stress and crisis, people do not always understand everything they are told, as they are in a state of denial or feel overwhelmed. The counsellor should not hesitate to be repetitive. Someone who understands and accepts information correctly will show this in some way. The counsellor should repeat statements of support or fact as often as necessary to ensure that the client clearly understands what must be done about risk, illness and health management.

(7) ***Summarizing.*** Many people who are stunned by news of their infection may respond by talking quickly and trying to provide more detail – or ask more questions – than the counsellor can absorb or comprehend. It is then helpful for the counsellor to interrupt at times and summarize what has been said. This is very much like paraphrasing in that it helps to ensure that each understands the other correctly. Summarizing also provides guidance and direction to both as they try to sort out emotions, deal with practical matters and make plans. A summary puts together a number of the client's paragraphs, or an entire phase of a session or may even cover the full session. It thus resembles a combination of Reflection of Feeling and Paraphrasing but over a longer period of time. At the end of each session, the counsellor should summarize the salient points of the discussion, highlighting decisions which have been made and need to be acted on.

(8) ***Confrontation.*** Many people become so preoccupied with their fears that they cannot see the *connection between their behaviour and the responses of others*. Confrontation involves a direct examination of incongruities and discrepancies in the client's thinking, feeling and/or behaviour. It calls attention to possible forms of self-deception, games, resistance, denial and evasion. It challenges the client to begin new, less destructive ways of behaviour. The counsellor also shows how *thoughts and actions, behaviour and consequences* are related – for example, "Have you noticed that when you withdraw and do not speak to your family, they get very irritated with you?" Because it is a highly intrusive skill, timing is very important. A strong relationship and rapport must be established. The confrontation should be delivered in an atmosphere of warmth, caring and concern.

(9) *Respecting.* The counsellor should appreciate that people see and cope with their predicaments in uniquely personal ways, determined by culture, social class and personality. Counsellors must respect clients' views and beliefs and build on them. They should show respect, for instance, by asking a client to explain aspects of the culture or personal belief which are strange to them – for example, "You feel strongly about this. I don't know about it. Tell me more about it".

(10) *Structuring or Prioritization.* Structuring means helping the client to see how facts and feelings are related. It determines what needs immediate attention and what can be put off until later. It is an essential part of planning and probably one of the most critical skills in counselling.

In summary, counselling succeeds only to the degree that counsellors can communicate at their clients' level of comprehension. Counsellors must communicate with absolute clarity, frequently checking their clients' interpretation and comprehension of their explanations. They must always adapt their language and style to their clients' culture and traditions.

3. ESSENTIAL STAGES OF COUNSELLING

Stage One – Forming Rapport and Gaining the Client's Trust.

At the beginning, clients may react in many different – sometimes contradictory – ways to a counsellor. The counsellor must spend time in encouraging trust and building a rapport with the client. He/she may do this by letting the clients tell their life/event stories in their own way. The counsellor may find the stories disjointed or rambling but must let them continue, while noting what is highlighted or played down or ignored.

Stage Two – Definition and Understanding of Roles, Boundaries and Needs.

Explaining and making clear to the client the roles and boundaries of the counselling relationship is an essential part of counselling. Establishing and clarifying the client's needs and goals – with the most urgent and important ones to be addressed first, followed by more general, long-term issues also need to be done before ongoing counselling sessions can begin. At this point, the counsellor also begins taking a case history. in effect just helping the client to tell his/her story in a different, and more orderly way. The history will include basic personal data as well as information on a client's beliefs, knowledge and concerns about HIV infection. The counsellor should use the history-taking as a means of solidifying the helping relationship, asking questions that are directly related to the client's concerns and, at the same time, geared to the client's needs in terms of his/her ability to use the resources available.

Stage Three – Process of Ongoing, Supportive Counselling.

Encouraging the client to begin a consideration of possible options and assessing possible solutions/decisions and their implications. Ongoing counselling focuses on enabling the client to take charge and move towards change. This stage also involves supporting and encouraging the expression of intense emotions like fear and anger by the client. Discussion of the client's plans for informing and involving the family and other close associates in cases of HIV infection and AIDS also occupies a lot of time and attention. Basically, counselling consists of supporting and sustaining work on the selected problems and monitoring of the progress towards the mutually decided goals.

Stage Four – Closure or Ending the Counselling Relationship.

After the client has shown willingness to formulate plans and has carried some of them through with a fair degree of success, counselling enters the end stage. The counsellor ends the relationship only when it is certain that the client: (1) is maintaining the necessary changes in behaviour; (2) can cope and adequately plan for day-to-day functioning; and (3) has a support system (family, friends, support groups, etc.). The ending must be carefully planned and discussed with the client as the client, although functioning adequately, may feel unable to carry on without the counsellor's help and a strong attachment/bond will have developed between the two people. The counsellor may increase the intervals between visits so as to let the client try and be independent, while knowing the counsellor is still available. Also, the client should be assured of being able to return to counselling whenever this is necessary.

4. SUPPORTIVE AND NON-SUPPORTIVE BEHAVIOUR

Some parts of a counsellor's behaviour readily support the counselling process, while others can bring it to a halt very quickly. A number of each of these types of behaviour are summarized in the two tables below. It should be noted that they are defined as supportive or non-supportive within a particular cultural context. Wherever counsellors are working, they will need to take note of the types of behaviour in the culture that would be seen as supportive or non-supportive in counselling.

EXAMPLES OF SUPPORTIVE BEHAVIOUR IN A SELECTED CULTURE

Verbal	Non-verbal
Uses language that the client understands	Uses a tone of voice similar to the client's
Repeats in other words and clarifies client's statements	Looks client in the eye
Explains clearly and adequately	Nods occasionally; uses facial expressions
Summarizes	Uses occasional gestures
Responds to primary message	Deeps suitable conversational distance
Encourages: "I see", "Yes, go on"	Does not speak too quickly or too slowly
Addresses client in a manner appropriate to the client's age	
Gives needed information	
Uses humour or other means of reducing tension	
Does not criticise or censure the client	

EXAMPLES OF NON-SUPPORTIVE BEHAVIOUR IN A SELECTED CULTURE

Verbal	Non-verbal
Advising	Looking away frequently
Preaching and moralizing	Keeping an inappropriate distance
Blaming, judging and labelling	Sneering
Cajoling (persuading by flattery or deceit)	Frowning, scowling and yawning
"Why" questions, interrogating	Using an unpleasant tone of speech
Directing, demanding	Speaking too quickly or too slowly
Excessive reassuring	Moving around too much, fidgeting
Straying from the topic	Having a blank facial expression or staring
Encouraging dependence	
Patronizing (condescending) attitude	

SUMMARY

Counselling is both an art and a science, and requires not only a knowlege of HIV infection but also self-knowledge, self-discipline and restraint. The counsellor must achieve a balance between warmth and acceptance, on the one hand, and objectivity, on the other. Approaches to counselling are likely to vary but certain essential qualities in a counsellor should exist or be developed. These include caring, empathy, self-awareness, cultural sensitivity and patience. The specific counselling skills or techniques that increase effectiveness of the process involve, among others, active attending, reflection of feeling, questioning, interpretation, confrontation and summarizing.

The counselling relationship with each client goes through four stages, each with its own particular characteristics and each calling for certain actions by the counsellor. Stage One is forming rapport and gaining the trust of the client. Stage Two involves demystifying the counselling process and its boundaries and beginning the process of history-taking and needs'-definition; stage Three consists of the actual work of supporting the client's decisions and feelings and helping him/her to move towards change. Stage Four signifies the ending of the counselling relationship once the client seems adequately equipped to function effectively and be supported by his/her own environment.

MODULE 5

SEXUALITY, SENSITIVE ISSUES AND RISK REDUCTION

MODULE 5

SEXUALITY, SENSITIVE ISSUES AND RISK REDUCTION

Objectives: (a) To enable the trainees to accept a range of sexual practices as normal.

(b) To enable the trainees to build skills in introducing and discussing sensitive issues with clients.

(c) To enable the trainees to build skills in discussing risk reduction.

(d) To enable the trainees to correctly demonstrate condom use.

(e) To enable the trainees to correctly demonstrate the use of bleach.

Time to complete the Module: 3 hours 45 minutes.

SUMMARY OF ACTIVITIES

(1) Large group discussion: Being comfortable with sexuality and sexual issues.
(2) Small group work: Sexual terminology.
(3) Small group work: Talking and thinking about sexual behaviour.
(4) Paired exercise: Developing communication skills to discuss sensitive issues related to sexuality.
(5) Brainstorming: Safer sex and risk reduction.
(6) Game and Demonstration: Correct condom use.
(7) Demonstration of use of bleach
(8) Self assessment: Review questions.

Activity 1: LARGE GROUP DISCUSSION: BEING COMFORTABLE WITH SEXUALITY AND SEXUAL ISSUES (15 minutes)

The aim of this activity is to desensitize trainees so that they can comfortably discuss sex and sexuality in a non-judgemental way.

The trainer asks trainees to suggest words or phrases that would help to define *sex*, *love*, *sexuality*. Next, he/she asks the group for their ideas about why it is important for counsellors to be able to openly discuss sexual issues and sexuality.

Record all these ideas on a flip chart, so that the trainees and trainer can get an overall picture of the group's inputs. End the activity by stressing the importance of a counsellor's comfort-level about sexuality and related issues in helping his/her clients to open up and deal with their concerns or dilemmas.

Activity 2: SMALL GROUP WORK: SEXUAL TERMINOLOGY (30 minutes)

This session is designed to practice talking about sex and sexual terminology, and to have trainees feel more comfortable referring to sexual activities.

Divide trainees into small groups of 4-6 people. Distribute worksheet 1. Ask each group to come up with acceptable and slang terms for each of the given terms in their local language. After 15-20 minutes have the trainees re-assemble as a full group. Ask each group member read out one word from their group's list in the large group. By practising this skill of using acceptable sexual terms, they will reduce possible, future difficulties in talking to clients about sexual behaviours. Wrap up this session by stating that a good counsellor should be able to select the appropriate words to refer to any of these sexual terms without offending the client, and without feeling too uncomfortable.

Activity 3: SMALL GROUP WORK: TALKING AND THINKING ABOUT SEXUAL BEHAVIOUR (40 minutes)

This activity provides an opportunity to explore the differences between one's thoughts and feelings in different situations and to consider how one's feelings affect one's responses to different situations.

Divide participants into groups of three or four people. Give each of the groups one of the listed situations and ask them to take it in turns to consider the following issues in the given situations. Allow 15 minutes for the groups' discussions. Emphasize that the trainees should not be putting themselves into a counsellor's role for this exercise but rather talking about how they react *personally*, as individuals.

How do you *feel* ?
What do you *think* ?
What do you *do* ?

Next, ask one member from each group to share briefly the major points of discussions from all three angles (think, feel, do) for their situation(s). The trainer summarizes bringing out the various patterns of sexual behaviour prevalent in the community and the kind of judgements people make. The trainer further emphasizes the range of "*normality*" in sexual activity and reinforces the need to be non-judgemental. This activity should take about 40 minutes.

Situations:

- Your child has come to you and asked how babies are made.
- Your best friend has just found out that her partner is having a sexual relationship with someone else.
- A young man in a group you are talking to, asks you what an orgasm is.
- You discover your son is having sex with commercial sex workers.
- You find that when you urinate, you have a discharge.
- One of your colleagues tells you that they think they might have an STD.
- Your daughter asks you what the term "anal sex" means.
- You notice multiple needle marks on the arm of your friend; he confesses he is an IV drug user.

(This exercise is adapted, with permission, from an IPPF Counselling and Sexuality training exercise).

Activity 4: PAIRED EXERCISE: DEVELOPING COMMUNICATION SKILLS TO DISCUSS SENSITIVE ISSUES RELATED TO SEXUALITY (30 minutes)

This activity builds skills among trainees for discussing sensitive issues and increases their awareness of the associated discomforts. The trainer starts by asking the group for examples of sensitive issues. Then he/she divides the group into pairs and explains the activity:

> "One of the pair will act as counsellor and the other as client. 'Chits' or small pieces of paper will be passed to the 'client' in each pair containing the description of a sensitive counselling scenario. The counsellor should try to help the client with his/her concern or dilemma."

Chits with the situations are distributed to all the pairs so they can begin the activity. After 10 minutes, the full group re-assembles and each of the counsellors first, and then the clients, share their experience (feelings and thoughts) with the group. The trainer concludes the session by using Overhead #1 and going over the five guidelines listed.

Counselling Scenarios:

- I suspect my girl friend also has other boy friends but I love her. I am afraid of AIDS but she gets very angry and tells me I do not trust her when I ask her about other boys. What can I say the next time I see her?
- Besides my wife, I have a regular girl friend. I always use a condom to avoid a pregnancy but she insists I should not use a condom during her menstruation period as she says that is a safe period. What shall I do?
- I think that my son is using drugs, but he has not talked to me about it yet. Should I bring it up?
- My wife and I have occasional anal sex and have been doing this for years. I was recently told I can get AIDS – I am now afraid and have come to you for advice.
- I am afraid of oral sex. Is it bad? Am I in danger of infection, particularly AIDS?
- I am a 17-year old boy. I have a boy friend with whom I have anal sex regularly. I do not want to stop but I am worried it may not be healthy for me.

Activity 5: BRAINSTORMING: SAFER SEX AND RISK REDUCTION (30 minutes)

This activity shows trainees how to identify behaviours with clients that will reduce their exposure to risk of HIV transmission.

The trainer draws a line down the middle of a large sheet of paper or board and heads one side as "Good things" and the other side as "Bad things" like shown below.

GOOD THINGS	BAD THINGS

The group offer their ideas about good things one enjoys or likes or gets and bad things or the negatives about sex. Once the paper or board is full, the trainer brings the group around to considering ways/behaviours by which the good things of sex can be kept and the bad things (risks) avoided or reduced. He/she asks trainees to summarize the major points that have been shared. Overhead #2 is shown to highlight safer sex options.

The trainer repeats the same brainstorming and listing process for using drugs.

Activity 6: GAME AND DEMONSTRATION: CORRECT CONDOM USE (45 minutes)

This activity aims to make all trainees more experienced at discussing and demonstrating condom use. Hand out a set of the condom cards to sub-groups of three trainees. Make copies of the condom cards for each group and mix them up. Ask the groups to put the cards in order.

Each trainee needs a condom for this next part of the activity. Ask all trainees to unwrap the condom and handle it. Some trainees can try to inflate the condom. Certainly they should all stretch the condom to see how strong the condom is.

After 5-10 minutes, the trainer demonstrates how to use a condom using a penis model, bottle or banana. State the steps as you carry out the demonstration. The trainees should correct any mistakes in the order/sequencing of their cards. Then distribute condoms, models and tissue paper (for wiping lubricant off fingers) to all the trainees. Each trainee should act out teaching one of the group members how to use the condom while the other monitors (by silently reading the cards) in pairs. Each should take a turn.

Then discuss how they feel about teaching condom use. In what situations might they/might they not be comfortable teaching how to use a condom? What prevents or makes people reluctant to use condoms?

Activity 7: DEMONSTRATION OF THE USE OF BLEACH (15 minutes)

This activity aims to provide all the trainees with experience in the correct use of bleach to disinfect needles and syringes and other injecting equipment. The trainer requires a packet of bleach, one litre container, a teaspoon, a syringe and needle, a bowl and water. The trainer demonstrates the preparation of the solution of bleach and how to flush the syringe and needle first with the bleach solution and then with water. The trainer also discusses sterilization of syringes by boiling them for 20 minutes.

Activity 8: REVIEW QUESTIONS (15 minutes)

Trainees fill up the worksheet 2 within 10 minutes. Trainees can discuss their answers with a partner or with the trainer.

WORKSHEET 1: For Activity 2

GROUP WORK – SEXUAL TERMINOLOGY

Technical English	Acceptable/ Local language	Slang/ Colloquial
1. Sexual intercourse		
2. Semen		
3. Ejaculation		
4. Penis		
5. Vagina		
6. Masturbation		
7. Orgasm		
8. Breasts		
9. Anal intercourse		
10. Kissing		
11. Oral sex		
12. Erection		
13. Buttocks		
14. Condom		
15. Homosexual		

The group offer their ideas about good things one enjoys or likes or gets and bad things or the negatives about sex. Once the paper or board is full, the trainer brings the group around to considering ways/behaviours by which the good things of sex can be kept and the bad things (risks) avoided or reduced. He/she asks trainees to summarize the major points that have been shared. Overhead #2 is shown to highlight safer sex options.

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This activity aims to make all trainees more experienced at discussing and demonstrating condom use. Hand out a set of the condom cards to sub-groups of three trainees. Make copies of the condom cards for each group and mix them up. Ask the groups to put the cards in order.

Each trainee needs a condom for this next part of the activity. Ask all trainees to unwrap the condom and handle it. Some trainees can try to inflate the condom. Certainly they should all stretch the condom to see how strong the condom is.

After 5-10 minutes, the trainer demonstrates how to use a condom using a penis model, bottle or banana. State the steps as you carry out the demonstration. The trainees should correct any mistakes in the order/sequencing of their cards. Then distribute condoms, models and tissue paper (for wiping lubricant off fingers) to all the trainees. Each trainee should act out teaching one of the group members how to use the condom while the other monitors (by silently reading the cards) in pairs. Each should take a turn.

Then discuss how they feel about teaching condom use. In what situations might they/might they not be comfortable teaching how to use a condom? What prevents or makes people reluctant to use condoms?

Activity 7: DEMONSTRATION OF THE USE OF BLEACH (15 minutes)

This activity aims to provide all the trainees with experience in the correct use of bleach to disinfect needles and syringes and other injecting equipment. The trainer requires a packet of bleach, one litre container, a teaspoon, a syringe and needle, a bowl and water. The trainer demonstrates the preparation of the solution of bleach and how to flush the syringe and needle first with the bleach solution and then with water. The trainer also discusses sterilization of syringes by boiling them for 20 minutes.

Activity 8: REVIEW QUESTIONS (15 minutes)

Trainees fill up the worksheet 2 within 10 minutes. Trainees can discuss their answers with a partner or with the trainer.

WORKSHEET 1: For Activity 2

GROUP WORK – SEXUAL TERMINOLOGY

Technical English	Acceptable/ Local language	Slang/ Colloquial
1. Sexual intercourse		
2. Semen		
3. Ejaculation		
4. Penis		
5. Vagina		
6. Masturbation		
7. Orgasm		
8. Breasts		
9. Anal intercourse		
10. Kissing		
11. Oral sex		
12. Erection		
13. Buttocks		
14. Condom		
15. Homosexual		

WORKSHEET 2

REVIEW QUESTIONS

(1) In your own workplace or community, which of the risk practices would be most difficult to talk about?

_____

_____

(2) Explain the following terms:

Bisexual

_____

_____

Masturbation

_____

_____

Non-judgemental attitude

_____

_____

(3) How comfortable will you feel discussing sexual behaviour of your client if he/she is of the same sex?

☐ Very comfortable ☐ Comfortable

☐ Uncomfortable ☐ Very uncomfortable

(4) How comfortable will you feel discussing sexual behaviour if your client is of a different sex?

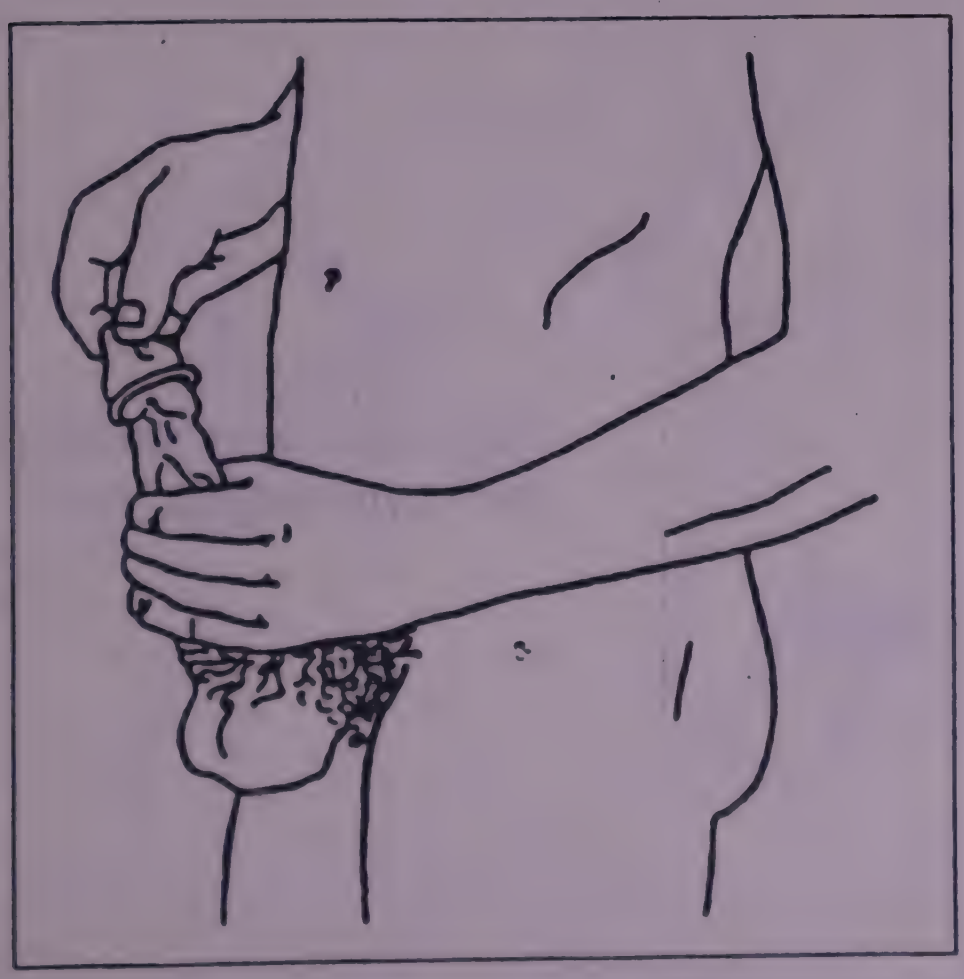
☐ Very comfortable ☐ Comfortable

☐ Uncomfortable ☐ Very uncomfortable

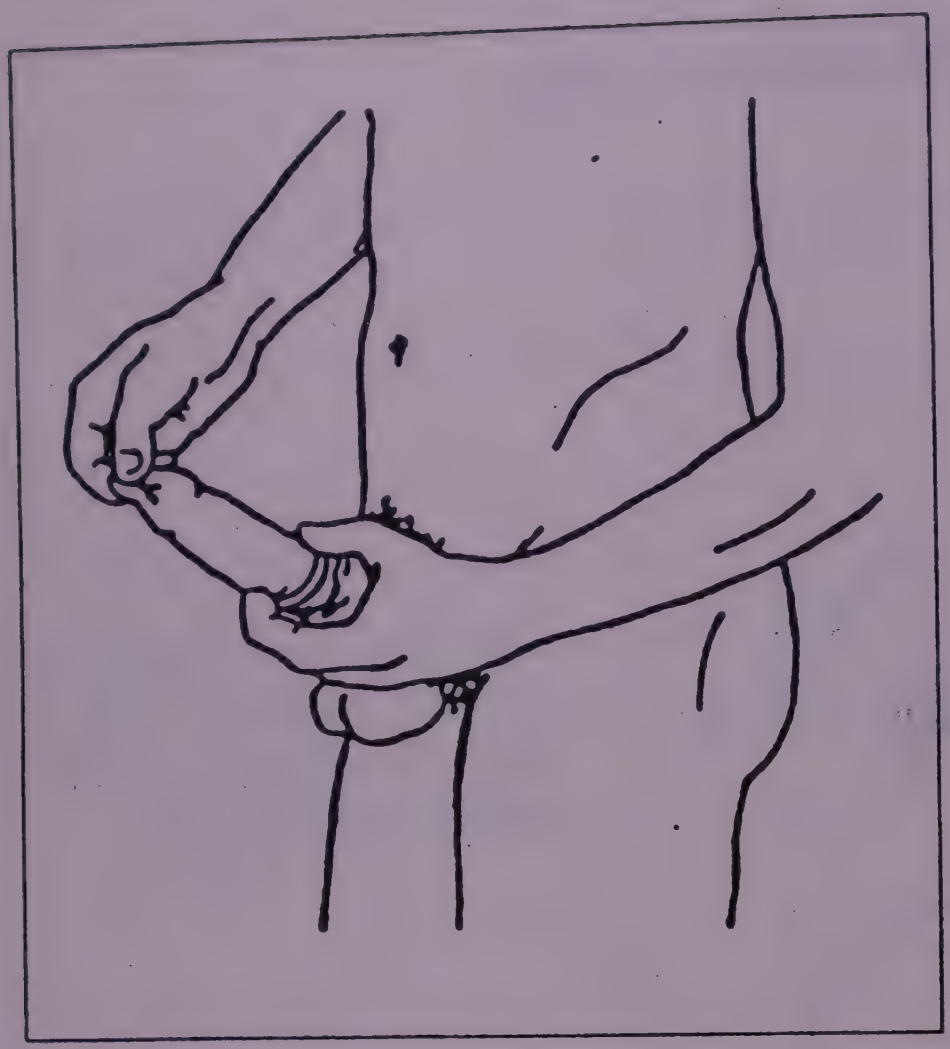
WORKSHEET 3: for Activity 6

CONDOM USE CARDS

Carefully open the package so the condom does not tear. Do *not* unroll condom before putting it on.



If not circumcised, pull foreskin back. Squeeze tip of condom and put it on end of hard penis.



Continue squeezing tip while unrolling condom until it covers all of penis.

Always put on a condom before entering partner.

After ejaculation
hold rim of condom and pull penis out before penis gets soft.

Slide condom off without spilling liquid (semen) inside.

Tie and wrap the condom (in paper, if available) then throw in dust bin. Wash hands.

Burn or bury the condom with other trash. Wash hands.

OVERHEAD # 1: For Activity 4

GUIDELINES ON TALKING ABOUT SENSITIVE TOPICS

(1) Ask direct questions so as to be clear about what is worrying the client and what he/she wants and expects from the counsellor.

(2) Establish the reasons for the client's concern or belief that he/she is infected or at risk of infection.

(3) Anticipate a certain degree of embarrassment at discussing sex; point out that you realize that people do not usually discuss it in such depth.

(4) Explain clearly why you must enquire into sexual practices and drug injecting – that it is in order to determine precisely what the client needs to do to prevent becoming infected or passing the infection on to others.

(5) Explain why you are asking questions about all the forms of transmission (viz. you are making sure that all possible risks are covered).

SEXUALITY AND SENSITIVE ISSUES

1. SEXUALITY AND SEXUAL OPTIONS

Sexual behaviour change of a client is an important component of STD and HIV counselling. Unfortunately, many counsellors find it difficult to get over being shy, embarrassed and put off dealing with the sexual issue; at other times, they are judgemental and label a sexual behaviour as not normal. Counsellors will need the essential 4 C's - Compassion, Care, Communication and Counselling - to achieve success. It is also important to have basic knowledge of sexuality and the range of sexual behaviours.

1.1 What is Sexuality?

It actually refers to gender - male or female - but has been relegated to imply "doing" something, such as intercourse/orgasm, or to the vagina, penis - the genitals. Sexuality is a more complex phenomenon which is difficult to define but perhaps easy to understand. Sexuality refers to the total sexual makeup of an individual. Sexuality includes sex, sexual behaviour, sexual intercourse. It is expressed in many physical ways. It is not confined to sexual intercourse but includes touching, talking, embracing, fantasizing, kissing, caressing or just holding hands. In addition to covering the physical aspects, sexuality also encompasses feelings, attitudes, values and preferences. It involves a lot of caring and sharing. Understanding sexuality is important for safer sex behaviour.

1.2 What Exactly is Normal?

Today it is recognised that there are many variations of sexual behaviour. No two people behave exactly the same way sexually. On the other hand, we all like to think that how *we* act and how *we* think about sex is "normal". In reality, our thinking has been conditioned by culture, tradition, society and our own emotions and experiences. The example may be given of homosexuality. A range of responses are expressed by different people about this: "They are unnatural"; "Should not be tolerated"; "It is abnormal"; if found in a workplace "They should be ostracised or sacked"; "It is an alternative sexual behaviour and homosexuals are as good as heterosexuals".

Whatever may be the beliefs or personal views, counsellors must be non-judgemental in viewing the client as a person requiring compassion, care and help to practice safer sex rather than concentrating on changing the sexual orientation of the person.

Certain criteria to evaluate what is "normal" in a relationship could be:

(1) *Consent* between the two partners to enact what gives them *mutual* pleasure, e.g. oral sex, variations in coital positions, anal sex;

(2) Any sexual activity that does not cause physical or mental harm;

(3) It should be a private affair - not public;

(4) The activity should not be exclusive (while keeping in mind that penile - vaginal insertion is the usual and necessary one for procreating), e.g. one partner insisting that only oral sex should be done.

The spectrum of sexual behaviours is wide. Some those connected with sexual behaviour in the context of STDs and HIV/AIDS infection are mentioned:

(1) ***Abstinence***: Keeping away from sex. Culturally, in India and other parts of the region, a good number of young people believe that sexual intercourse should only be done after marriage. Virginity is still prized. While recommending safer sex, those wishing to practice abstinence should be encouraged. Definitely, they should be made knowledgeable of the consequences of unprotected sexual intercourse.

(2) ***Masturbation***: Means stimulating one's own genitals to reach orgasm. Most males masturbate with their hands, while some rub their penis against the surface of the bed, or use some object. Females also masturbate in the same way. Masturbation is still a taboo topic. Men masturbate more readily than women but few view it in a positive light. Now, masturbation can be considered as one of the satisfactory and harmless ways to achieve sexual satisfaction. The only harm it does is the guilty feelings it may produce in those who are riddled with the many misconceptions regarding masturbation. Many may reject the myths, the taboos and the "don'ts" about masturbation but still feel anxious, uncomfortable or guilty about it. It is important that while attempting to change a client's behaviour, he/she must be made to understand the value of masturbation as a safer sex procedure.

(3) ***Nocturnal emissioms***: If a male does not have any other method of sexual outlet, he will experience "wet dreams" or nocturnal emissions. The person will have a dream with erotic content during which ejaculation will occur. This is perfectly normal.

(4) ***Oral sex***: Using the mouth in any way on portions of the body is referred to as oral sex, but most people believe it is specifically using the mouth on the partner's genitals. "Fellatio" is when the female uses her mouth on the partner's genitals. "Cunnilingus" is when the male uses his mouth to stimulate the female's vagina. When HIV infection is a possibility or if infections in the mouth are present, oral sex should be avoided or the male may wear a condom while engaging in fellatio.

(5) ***Homosexuality***: Persons who choose to share their bodies sexually with persons of the same gender are called homosexuals. In a male-male relationship, the person may be termed homo-phile or gay. In a female-female relationship the person is known as a lesbian. Why homosexual behaviour is preferred by some is still debated. The term "alternative sexuality" is becoming a more acceptable term. Attitudes towards homosexuality are changing although there is still a great deal of antagonism, contempt, anger and misunderstanding among people. Health professionals are now coming to accept homosexuality more as a sexual variation than as an illness. Sometimes, homosexual experiences may be situational as occurs in prisons, some boarding schools and colleges. The person may participate voluntarily or be forced even when he/she usually prefers heterosexual intercourse. Bisexuals are persons who are sexually attracted to both men and women.

Homosexual behaviour is dangerous only if penetrative anal sex occurs. Fine injuries or ruptures around the anus help the meeting of HIV infected blood or semen with the blood of the uninfected partner. Oral sex which is a popular sexual activity with homosexuals can be unsafe if a partner has mouth, vaginal or penile lesions. *Condom usage on every occasion is a must.* Often behaviour like "cruising", where a person goes out to find an unknown partner or stranger in a train, exhibition etc. is very unsafe behaviour and the dangers should always be explained to the client.

On counsellors and sexuality

A few final words for counsellors on sexuality

- they should be comfortable and familiar with the terminology of human anatomy, physiology and sexual behaviour;
- they should understand the basic underlying processes of reproductive and sexual physiology;

- they need to appreciate the range and variety of sexual expression in the human culture;
- they must recognize the social implications of human sexual behaviour and the relative nature of these implications in different societies;
- they have to work at being able to deal candidly with their own sexuality in relation to oneself and others, and reflect on the related moral and ethical dilemmas.

2. GUIDELINES ON TALKING ABOUT SENSITIVE TOPICS

It is necessary for counsellors to obtain an understanding, or history of the behaviour which may have exposed the client to HIV infection or AIDS. This means that counsellors must be able to gather and interpret information about very private – and sometimes illegal or socially condemned – behaviour. There is no simple formula for getting people to talk about topics such as their own sexual activities, drug injecting or responses to infection from blood transfusion. Effective discussion of sensitive topics will depend in large part upon the ability of the counsellor to:

- gear his/her communication to the emotional and intellectual level of the client;
- make the client feel safe, secure and accepted by establishing a supportive relationship; and
- demonstrate his/her own ease in talking about topics usually avoided in ordinary social life or in medical consultations.

Whatever approach a counsellor uses, it will require skill, tact and sensitivity towards the client. With some clients, counselling can be a process which develops gradually and may need to be eased into slowly. Early on, a rapport will need to be established, together with an overall atmosphere that helps the client to develop a feeling of safety and trust, without which the counselling process will not be completely successful. The counsellor's style must therefore be *reassuring, confident and direct*, but considerate of the client's feelings and fears and acknowledging the client's difficulty.

The following specific guidelines on talking about sensitive topics will be useful to counsellors:

(1) *Ask direct questions so as to be clear about what is worrying the client, and what he/she wants and expects from the counsellor.*

Example: What do you want from me (this clinic, hospital, etc.) right now? What made you decide to come here now?

(2) *Establish the reasons for the client's concern or belief that he/she is infected or at risk of infection.*

Example: You tell me that you are afraid you have AIDS. Tell me what you know about the ways in which people become infected. In which of these ways are you most at risk?

(3) *Anticipate a certain degree of embarrassment at discussing sex; point out that you realize that people do not usually discuss it in such depth.*

Example: We do not usually talk very openly about sex in our country. But, now, since you believe you may have been at risk of infection, you and I must determine the degree of risk. To do that, I have to ask some very specific questions. Most people feel a bit embarrassed by these questions, and you may too. For example, I need to know how many sexual partners you have had over the past six months.

(4) *Explain clearly why you must enquire into sexual practices and drug injecting – that it is in order to determine precisely what the client needs to do to prevent becoming infected or passing the infection on to others.*

Example: HIV is transmitted in a number of quite specific ways. You know that sharing needles is dangerous for you and for others. What can you do to keep yourself free of infection, or to protect other people?

(5) *Explain why you are asking questions about all forms of transmission.*

Example: Sometimes people are offended when I ask about practices that seem strange or even repulsive because they are not common in this area. But, people travel, and sometimes experiment, so we must make sure that all the possible risks are covered.

In such interviewing, the counsellor should use the formal expression first (e.g. vaginal intercourse). If it is not understood, the slang expression should be used and the client asked which one is preferred. The client must not feel that the counsellor is making any moral judgement on any sexual behaviour or other risk behaviour.

The counsellor should check frequently to make sure that the client understands what is being said – for instance, by asking the client to repeat in his/her own words what the counsellor has been saying.

The counsellor should also ensure by asking the questions given below that everyone being counselled for the prevention of HIV infection receives and understands the following 3 essential messages:

"There is no cure for HIV infection. Prevention is the only defence at the present time."

Questions: How do you think that HIV infection is spread? If you want to stay free of infection, what changes will you have to make? Changes of this kind are difficult for most people – what can we do to help you make them and not fall back into the old ways? What will you tell others (spouse, partner) about why you are changing your sexual behaviour?

"HIV can be transmitted through vaginal and anal sex; sharing needles; and contaminated blood."

Questions: What do you think people find most difficult when they give up (whatever the risk behaviour is)? What do you think might be hardest for you? When you say you do some risky things, what do you mean?

"HIV transmission can be prevented only through abstinence, or sex without exposure to blood, semen or vaginal/cervical fluids. To lessen the risk of sexual transmission, men should use a condom each time and from start to finish. Women should ensure that their partner uses one. The more sexual partners, the greater the risk of exposure. Drug injectors should not share with anyone else syringes or other drug-related instruments that pierce the skin."

Questions: Do you think it is possible for you and your spouse/partner to abstain from sex? Have you tried condoms? When you and your spouse/partner talk about condoms, how comfortable is each one of you? What do you know about the best way to use a condom?

The client should be given time and information with which to discuss appropriate means of infection control and avoidance (see Module V1 for "Practical Information for People with HIV Infection and Disease").

This information must be communicated in a language and terms that the client understands. The counsellor will need to try different versions and to vary it for individual cases.

Clients may be given a pamphlet or leaflet containing information on HIV transmission, prevention and condom use. If they cannot read, the counsellor should go over the details, using questions to double-check that the information is being understood. Clients who can read and write should be encouraged to make notes and take them home. Follow-up questions might also be used.

3. CULTURAL FACTORS INFLUENCING SEXUAL BEHAVIOUR

It is important to note that, in some cultures, the absence of penetrative sex is the same as not having had sex at all – suggestions for safer sexual practices may therefore not be well received in many cultural settings. In these cases, it must be reiterated that the only *completely* safe behaviour is a monogamous long-lasting relationship in which neither partner is infected with HIV.

The counsellor should anticipate that some of this information may be met with embarrassment, laughter, turning away, or even anger depending on the cultural context. On religious grounds, for example, a person might become angry with a counsellor who mentions masturbation. As always, the counsellor should respect the client's beliefs, but point out that everyone is entitled to complete information, whether or not a decision is made to act on it.

It is imperative that the counsellor acknowledge that changing sexual patterns or behaviour, and maintaining that change, is very difficult. Cultural expectations about sex roles and sexuality, and about childbearing, must be discussed. A suggestion about condom use which makes good sense to the counsellor may be perceived by a client as an assault on his masculinity or as a threat to the relationship with the spouse.

4. TALKING ABOUT LEVELS OF RISK

The risk associated with some sexual practices has not been definitely established. The counsellor must be as certain as possible that the client understands the relative degree of risk involved. In discussing these levels of risk, it will once again be necessary for the counsellor to engage the client in talking about taboo topics or unfamiliar practices. Messages about relative degrees of risk will be most clearly understood after information about safer sex has been given and its implications discussed.

5. TALKING ABOUT THE USE OF CONDOMS

The counsellor must emphasize to clients of both sexes the importance of consistent use of condoms. Even if there is strong resistance to the use of condoms, clients must be helped to assess realistically the risks to themselves and others of not using them if they have been at risk of infection or intend to practice unsafe sexual or other behaviour.

The counsellor should be forthright in telling clients that condoms need getting used to, and that they will need to practice putting them on. Clients also need to be told that condoms are not foolproof against tearing or leakage, and must be put on carefully and properly.

Instructions for condom users – For maximum protection against HIV infection, condoms must be used correctly. Make sure that you understand and follow these instructions:

- Use a new condom every time you have intercourse. Check the expiry date before use.
- Always put the condom on the erect penis before intercourse begins.
- In putting on the condom, squeeze the nipple or empty space at the end of the condom in order to remove the air. Do not pull the condom tightly against the tip of the penis; leave the small empty space (one or two centimetres) at the end of the condom to hold the semen.
- Unroll the condom all the way to the base of the penis.
- If the condom tears during intercourse, withdraw the penis immediately and put on a new condom.
- After ejaculation, withdraw the penis while it is still erect. Hold the rim of the condom as you withdraw, so that the condom does not slip off.
- Remove the condom carefully so that seminal fluid does not spill out. Dispose of used condoms in a closed receptacle for waste.
- If a lubricant is desired, use a water-based one, since petroleum jelly may damage condoms.
- Do not use saliva as a lubricant – it is ineffective and may lead to breaking of the condom.
- Store condoms away from excessive heat, light, and moisture, as these cause them to deteriorate and perhaps break. Do not keep them in the glove compartment of cars or wallet for long periods of time.
- Condoms that are sticky or brittle or otherwise damaged should not be used.

These instructions may prove difficult to follow by even the well educated. It is preferable that counsellors become conversant with them and explain them in simple language. Use of simple graphic material (adapted to the culture) is recommended. Consider adapting the culturally appropriate graphics already in use by family planning associations in your area.

6. TALKING ABOUT THE USE OF BLEACH TO DISINFECT SYRINGES AND NEEDLES AND OTHER INJECTING EQUIPMENT

The counsellor must emphasize the importance of avoiding using drugs. The counsellor must also emphasize that if drug use can not be avoided, then it is important to avoid injecting drugs. If the person cannot avoid the use of injecting drugs, then give instructions not to share needles, syringes and other injecting equipment. Explain the risk of HIV transmission through sharing needles and syringes and other skin piercing instruments. If the injecting drug user cannot avoid the use of sharing needles or other injecting equipments, then instruct the person to do the following:

The first step is to flush the equipment several times with clean water to get rid of the blood or other debris stuck inside the equipment. Then, either:

sterilize by boiling the injecting equipment for 20 minutes.

or

use the bleach in the following manner:

- A level teaspoon of household bleach should be mixed with a litre of water.
- Put the solution into a bowl and flush *twice* the syringe and needle with the solution.
- Flush *twice* the syringe and needle with water.

SUMMARY

Human sexuality is a very important aspect of people's lives and needs to be well understood by counsellors when doing HIV prevention and supportive counselling. It refers not only to sexual intercourse/activities but also to feelings, attitudes and values. What is considered as normal by one person in one society may be considered as abnormal by someone else in another social environment. It is important for counsellors to be non-judgemental about clients' sexual preferences and orientations and keep the focus on exploring safer sex options. Some of the sexual behaviours that need special attention in connection with STDs and HIV are: abstinence, masturbation, nocturnal emissions, oral sex and homosexuality.

To obtain an understanding of the client's behaviour which led to or places him/her at risk of HIV infection, the counsellor must be able to obtain information on such sensitive topics as sexual practices and drug injecting. This can be done only through informed questioning. Questions must also be used to ensure that all clients understand the basic information on HIV infection and its prevention. Clients must be given advice on safer sexual practices, but told that the only completely safe behaviour is sexual abstinence or a monogamous long-lasting relationship. The latter is particularly important in cultures in which advice on non-penetrative or safer sexual practices is not well received. In discussing levels of risk, counsellors will again have to talk to clients about sensitive topics, and will themselves need to decide how ready they are to talk about them. The consistent use of condoms must be emphasized and instructions given on how they should be used. Importance of not sharing needles and syringes and other injecting equipment should be emphasised and the use of bleach to sterilize injecting equipment should be explained.

MODULE 6

PRE- AND POST-TEST COUNSELLING

MODULE 6

PRE- AND POST-TEST COUNSELLING

Objectives: (a) To enable the trainees to recognize the information needs of the people who come for counselling and test negative or positive.

(b) To enable the trainees to build skills in risk assessment and in breaking of bad news.

Time to complete the Module: 2 hours 50 minutes.

SUMMARY OF ACTIVITIES

(1) Presentation: HIV antibody testing.
(2) Group work: Process of pre-test and post-test counselling.
(3) Role play: Pre-test and post-test scenarios.
(4) Exercise: Breaking the news.
(5) Review questions.

Activity 1: PRESENTATION: HIV ANTIBODY TESTING (30 minutes)

This presentation allows the trainer to review the reasons for HIV antibody testing and issues related to testing such as confidentiality, disease surveillance, record keeping, mandatory or voluntary nature of testing. The trainer makes the presentation on the two aspects of testing "Reasons" and "Issues" with the help of Overheads#1 & 2 *without* going into too much technical detail. The presentation lasts for 20 minutes followed by 10 minutes of group discussion or questions.

Activity 2: GROUP WORK: PROCESS OF PRE-TEST AND POST-TEST COUNSELLING (45 minutes)

The purpose of this activity is to help the participants to identify the critical questions and steps involved in pre-test and post-test counselling. Divide trainees into 5 groups. Give each group a card with a pre-test or post-test situation. Ask each group to make a list of the questions or steps related to the situation on the card. Give the groups 10 minutes for discussion. Ask each group to present their situation and justify their questions or steps. Allow 5 minutes for each group-presentation.

The trainer wraps up the session with summary points (taken from the Supplementary Reading) for pre-test and post-test counselling situations, emphasizing for the participants to recognise and respect the special needs of each client.

Activity 3: ROLE PLAY: PRE-TEST AND POST-TEST SCENARIOS (1 hour)

The two role plays are designed to help the trainees to understand that pre-test and post-test counselling are related activities. The trainer asks participants to form 2 groups.

Each group gets a card with Robin's scenario – one as pre-test and the other as post-test. Two volunteers in each group are recruited to play the roles of counsellor and client. Each group is instructed to prepare and rehearse their role play for 20 minutes. After this preparation time, the two sets of volunteers enact their scenario for the full group for 7–10 minutes each. After each role play, all the trainees discuss the main issues involved and the kind of counselling provided.

At the end of the two role plays, the trainer ends the activity, making sure that all trainees recognize the importance of linking pre- and post-test counselling. Allow about one hour for this activity.

Activity 4: EXERCISE: BREAKING THE NEWS (20 minutes)

This exercise aims at helping the trainees in realizing their own fears as counsellors about dealing with clients who have tested as HIV positive.

Ask trainees to write confidentially on a small piece of paper one fear/worry which they have about breaking the bad news of a positive test result to a client. The trainer emphasizes that this should be a concern or fear of the trainee-counsellors and not that of the client.

A volunteer collects all the papers in a basket, mixes them, and then gives one to each fellow trainee. Each trainee reads aloud what is written on his/her paper and decides whether this concern can be lessened by *increasing knowledge, or improving skills or acknowledging personal issues*. The trainer lists three areas on a flip chart as Knowledge, Skills, and Personal Issues. After each trainee decides in which category his/her paper comes, the trainer places a tick-mark under one of the three categories on the flip chart.

After all the worries have been listed, the trainer concludes with general remarks about the category where most concerns have come up as seen on the flip chart and the importance of all three (Knowledge, Skills and Personal Issues) in effective counselling. Allow 20 minutes for this activity.

Activity 5: REVIEW QUESTIONS (15 minutes)

At the end each trainee will complete the worksheet and return it to the trainer. The trainer reads out some responses at random and clarifies any misconceptions or ambiguities. This activity should take 15 minutes.

PRE-TEST AND POST-TEST COUNSELLING SITUATIONS: *For Activity 2*

One for each group

#1

List and record some of the things/questions a counsellor might do and/or ask during a pre-test situation.

#2

List and report some of the questions or steps a counsellor might ask and/or take during a post-test situation where the test result is negative.

#3

List and record some of the things/questions a client might do/say/ask after hearing a positive test result.

#4

Sam, a 22-year old student read about AIDS. In the last few years, he has had anal sex with several male partners and has never used a condom. He is not only worried about AIDS but also feels terribly guilty. He has not had the courage to talk about his sexual behaviour to anybody. Today he has come to the testing centre for a test. List some questions you would use as a counsellor in order to explore the problem.

#5

Ali, a 28-year old man donated blood for his father without any pre-test counselling. His blood sample was tested and found to be positive for HIV antibodies. He came to know that blood banks test for HIV. Now he wants to find out the test result for his blood on the phone. But the blood bank has advised him to come to the counsellor in the centre. The counsellor knows the test result. He has come today but is in a hurry to go back to his office as quickly as possible.

List some questions you would use as the counsellor to explore the problem.

ROLE PLAY: *For Activity 3*

PRE-TEST AND POST-TEST SCENARIOS

 # 1

Robin is a 32-year old married man with two children. He has been having an affair with another married woman, Sheila, for the last few years. A friend of Sheila has recently been diagnosed as infected with HIV. Robin is worried about his wife and children. He comes to you seeking help.

 # 2

Robin is a 32-year old married man with two children. He has been having an affair with another married woman, Sheila, for the last few years. He had gone for Sheila testing because he was worried after hearing about a friend who had been diagonsed as HIV positive. Robin had received pre-test counselling from you and has come back to you after the result. Robin has tested HIV positive. He disbelieves the test. He also expresses his concern about the future of his family.

WORKSHEET

REVIEW QUESTIONS

1. **Correct the sentence:**

   George came for an AIDS test.

   _____

2. **What is a "window period"?**

   _____

   _____

   _____

3. **List three types of people who may seek testing?**

   _____

   _____

   _____

4. **Give two reasons for not giving an HIV test result on the telephone.**

   _____

   _____

   _____

5. **What issues should be discussed with a person who tests HIV negative?**

   _____

   _____

   _____

OVERHEAD#1: *For Activity 1*

REASONS FOR DOING HIV ANTIBODY TESTING

1. **Compulsory/mandatory screening of blood for transfusion and blood products.**

   To prevent HIV being transmitted to the recipient.

2. **Disease surveillance (in an anonymous, unlinked manner).**

   To monitor the trend of HIV infection.
   To plan future prevention and control strategies.

3. **Voluntary, confidential Testing.**

   Upon a client's request.

4. **Research.**

   To develop vaccines/drugs.

OVERHEAD#2: *For Activity 1*

ISSUES RELATED TO HIV ANTIBODY TESTING

1. Confidentiality.
2. Disease Surveillance.
3. Record Keeping.
4. Mandatory Blood Testing.
5. Voluntary Blood Testing.
6. Informed Consent.
7. Travel Abroad - for a visit or education.
8. Hospital Testing for HIV.
9. Request from friends/family.

PRE- AND POST-TEST COUNSELLING

1. ROLE OF ANTIBODY TESTING

Voluntary testing services should be made widely available as part of AIDS prevention and control programmes. Access to such services should be facilitated and provision made for counselling. Both pre- and post-test counselling sessions should accompany testing – *or* the decision not to be tested. The information given at these sessions can be reinforced by providing written material.

Counsellors everywhere have to deal with wrong ideas and even anxieties about HIV antibody testing. The counsellor must ensure that the client understands what the test implies and what a positive or negative result means. Many people believe that a positive enzyme-linked immunosorbent assay (ELISA) means that they have AIDS, and this may cause great distress. The counsellor must deal with the fear and communicate the facts unambiguously. People whose test is negative may feel relieved and believe that they can go on living again in the same way as before. Preventive counselling must begin immediately to prevent this attitude. They must be told about the "window period" and what they should do to prevent acquiring or passing on the infection, and be urged to return for follow-up counselling.

People who are considering being tested for HIV infection must be given the information they need to be able to make a well-informed decision on whether to have the test. The information must be up-to-date and cover the technical aspects of testing and its medical and social implications. Confidentiality must be ensured.

Mandatory testing for HIV has no place in programmes for AIDS prevention and control. It is not recommended except for screening of donated blood prior to transfusion or of semen, or other cells, tissues or organs prior to transplantation. Such screening should not be carried out without consent and counselling, and confidentiality must be ensured.[2,3]

2. COUNSELLING ISSUES RELATED TO TEST-SEEKING

Testing raises many questions for the counsellor, not the least of which is how to assess clients' reasons and motivation for seeking a test.

People sometimes donate blood so as to have a pretext for undergoing an antibody test. The counsellor should discourage this practice. Those who do so miss the opportunity which counselling offers to discuss safe sexual practices and related matters.

In some places facilities for testing are not readily available. Where this is so, every effort should be made to emphasize preventive counselling, especially the need for behavioural change where there has been high-risk activity, and the maintaining of low-risk behaviour where behaviour change has been practised. Counselling, education, information, and support are all vitally important in bringing about and maintaining behavioural change.

3. PRE-TEST COUNSELLING

3.1 The Aim of Pre-test Counselling

Counselling before the test should provide individuals who are considering being tested with the information on the technical aspects of screening and on the possible personal, medical, social, psychological, and legal implications of being found either HIV-positive or HIV-negative. The

information should be given in a manner that is easy to understand and should be up to date. Testing should be seen as a positive act that is linked to changes in risk behaviour.

A decision to be tested should be an informed decision. Informed consent implies awareness of the possible implications of a test result. In some countries, the law requires explicit informed consent before testing can take place; in others, implicit consent is assumed whenever people seek health care. There must be a clear understanding of the policy on consent in every instance, and anyone considering being tested should understand the limits and potential consequences of testing.

Testing for HIV infection should be organized in such a way that minimizes the possibility of information disclosure or of discrimination. In screening, the rights of the individual must also be recognized and respected. Counselling should actively endorse and encourage those rights, both for those being tested and for those with access to records and results. *Confidentiality* should be ensured in every instance.

3.2 Issues in Pre-test Counselling

Pre-test counselling should be centred on two main topics: first, the person's personal history and risk of being or having been exposed to HIV (box #1); secondly, the client's understanding of HIV/AIDS and previous experience in dealing with crisis situations (box #2).

In assessing the likelihood that the person has been exposed to HIV, the following aspects of his or her life since about 1980 should be taken into account:

BOX #1: ***Assessment of Risk***

- Frequency and type of sexual behaviour and specific sexual practices; in particular, high-risk practices, such as vaginal and anal intercourse without using condoms, unprotected sexual relations with commercial sex workers, and drug injecting.
- Being part of a group with known high HIV prevalence or with known high-risk life-styles, e.g. injecting drug users, male and female commercial sex workers and their clients, prisoners, and homosexual and bisexual men.
- History of blood transfusion, organ transplant, or administration of blood or body products.
- Exposure to possibly non-sterile invasive procedures, such as tattooing and scarification.

BOX #2: ***Assessment of Psychosocial Factors and Knowledge***

- Why is the test being requested?
- What particular behaviours or symptoms are of concern to the client?
- What does the client know about the test and its uses?
- Has the client considered what to do or how he/she would react if the result was positive, or if it was negative?
- What are the client's beliefs and knowledge about HIV transmission and its relationship to risk behaviour?
- Who could provide (and is currently providing) emotional and social support (family, friends, others)?
- Has the client sought testing before and, if so, when, from whom, for what reason, and with what result?

This initial assessment should make it possible to discuss and assess the likelihood of the client's understanding: (a) the meaning and potential consequences of a positive or negative result; and (b) how change in behaviour can reduce the risk of infection or transmission to others.

Pre-test counselling should include a careful consideration of the person's ability to cope with a diagnosis and the changes that may need to be made in response to it. It should also encourage the person being counselled to consider why he or she wishes to be tested and what purpose the test will serve. When the counsellor enquires about personal history, it is important to remember that the client:

- may be too anxious to fully absorb what the counsellor says;
- may have unrealistic expectations about the test;
- may not realize why questions are being asked about private matters and therefore be reluctant to answer; and
- may not be willing to change behaviour irrespective of the result.

During pre-test counselling, it is also important that the client be told that current testing procedures are not infallible. Both false-positive and false-negative results occasionally occur, although supplemental (confirmatory) tests are very reliable if an initial test is positive. These facts must be clearly explained, together with information about the "window period" during which the test may be unable to assess the true infection status of the person.

In summary pre-test counselling should:[4]

- determine what that person *understands* about HIV and AIDS;
- provide factual *information* as needed;
- discuss potential *implications* of a positive and negative test result;
- explain and obtain *informed consent*;
- review the *test procedure*;
- assess the person's *ability to cope* with a positive result; and
- establish a *relationship* as a basis for post-test counselling.

Once a decision has been made to take the test for HIV antibodies, arrangements should be made to prepare for post-test counselling.

4. POST-TEST COUNSELLING

HIV testing can have three possible outcomes:

(1) a negative result;
(2) a positive result;
(3) an equivocal result.

4.1 Counselling after a Negative Result

It is very important to carefully discuss the meaning of a negative result (whether this was expected or not). The news that the result was negative is likely to produce a feeling of relief or euphoria, but the following points must be emphasized:

(1) Following possible exposure to HIV, the "window period" must have elapsed before test results can be considered reliable. This means that, in most cases, a minimum of at least three months must have elapsed from the time of possible exposure before a negative test can be considered to mean that infection did not occur. A negative test result carries greatest certainty if at least six months have elapsed since the last possible exposure.

(2) Further exposure to HIV infection can be prevented only by avoiding high-risk behaviours. Safer sex and avoidance of needle-sharing must be fully explained in a way that is understood and permits appropriate choices to be made.

(3) Other information on control and avoidance of HIV infection, including the development of positive health behaviours, must be provided. It may be necessary to repeat such explanations and for the counsellor and the person being counselled to practice together methods of negotiating these with others, in order to assist the client in introducing and maintaining the new behaviour.

4.2 Counselling after a Positive Result

People diagnosed as having HIV infection or disease should be told as soon as possible. The first discussion should be held in private and under conditions of confidentiality, and the client should be given *time* to absorb the news. After a period of preliminary adjustment, the client should be given a clear, factual explanation of what this news means. This is *not* a time for speculation about prognosis or estimates of time left to live, but for acknowledging the shock of the diagnosis and for offering and providing support. It is also a time for encouraging hope – hope that achievable solutions can be found to the resulting personal and practical problems. Where resources are available, it may also be justifiable to talk about possible treatments for some symptoms of HIV infection and about the efficacy of new antiviral drugs. Important practical information for people with HIV infection must be provided (see points 3.3 and 5).

After a positive result, the counselling relationship may enter a new phase. Crisis counselling will always be necessary, and usually also problem-solving counselling. The pre-test assessment can be used to determine the best way to tell the client about the test result. How the news is accepted will depend on the person's personality, psychosocial circumstances, previous knowledge of HIV, and cultural attitudes towards AIDS. The client must be told how to contact the counsellor during periods of severe stress. There should be some discussion of what may happen if employers or others learn that the person is HIV-infected. All the information previously given about safer sex, prevention of transmission, and maintaining health must be repeated. Follow-up visits must be arranged, often on a routine basis.

Counsellors must always stress *the individual's responsibility for changing behaviour to avoid infection or to limit, if not eliminate, the risk of transmission, and the life-long nature of the infection and of the risk of infecting others.*

How the news of HIV infection is accepted or incorporated often depends on the following:

(1) The person's physical health at the time. People who are ill may have a delayed reaction. Their true response may appear only when they have grown physically stronger.

(2) How well prepared the person was for the news. People who are completely unprepared may react very differently from those who were prepared and perhaps expecting the result. However, even those who are well prepared may experience the reactions described herein.

(3) How well supported the person is in the community and how easily he/she can call on friends. Factors such as job satisfaction, family life and cohesion, and opportunities for recreation and sexual contact may all make a difference in the way a person responds. The reaction of the news of HIV infection may be much worse in people who are socially isolated and have little money, poor work prospects, little family support, and inadequate housing.

(4) The person's pre-test personality and psychological condition. Where psychological distress existed before the test result was known, the reactions may be either more or less complicated and require different management strategies than those found in persons without such difficulties. Post-result management should take account of the person's psychological and/or psychiatric history, particularly as the stress of living with HIV may act as a catalyst for the re-appearance of earlier disturbance.

In some cases, news of HIV infection can bring out previously unresolved fears and problems. These can often complicate the process of acceptance and adjustment and will need to be handled sensitively, carefully, and as soon as possible.

(5) The cultural and spiritual values attached to AIDS, illness, and death. In some communities with a strong belief in life after death, or with a fatalistic attitude towards life, personal knowledge of HIV infection may be received more calmly than in others. On the other hand, there may be communities in which AIDS is seen as evidence of antisocial or blasphemous behaviour and is thus associated with feelings of guilt and rejection.

Counselling and support are most needed when reactions to the news of HIV infection or disease appear. Some reactions may initially be very intense. It is important to remember that such responses are usually a normal reaction to life-threatening news and as such should be anticipated.

The *psychological states* that develop in most people with HIV infection or disease revolve around *uncertainty* and *adjustment*.

HIV infection gives rise to uncertainty about hopes and expectations about life in general, but it may be felt mainly about family and job. An even more fundamental uncertainty may concern the quality and length of life, the effect of treatment, and the response of society, all of which are relatively unpredictable in terms of their long-term outcome. They need to be discussed openly and frankly but care should always be taken to ensure that *hope* and a *positive outlook* prevail.

In response to uncertainty, the person with HIV must make a variety of *adjustments*. Even the apparent absence of response may, in itself, be an adjustment through denial. People adjust to news of their infection or disease from the time they are first told. Their day-to-day lives will reflect the tension between uncertainty and adjustment. It is this tension that causes other psychological issues to assume more or less prominence and intensity from time to time.

There is no way of predicting the reaction to news of HIV infection or disease. Some people will go into shock and a state of crisis, then come around to acceptance, with medical care and counselling. Others will resort to denial, and face up to their condition only when they become too ill or weak to keep up the pretence.

Miller[5], in "Living with AIDS and HIV", writes that *shock* is a normal response to life-threatening news and has listed the following common shock reactions to diagnosis or infection :

- numbness/"stunned" silence/disbelief;
- confusion/distractibility/uncertainty about present and future circumstances;
- denial ("It can't be true", "Don't worry, things will be fine");
- despair ("Oh my God, everything is ruined");
- anger towards health staff, loved ones etc., over the impact on life and circumstances;
- fear of pain, death, disability, loss of bodily/mental functioning, loss of confidentiality/privacy;
- guilt/self-recrimination over the association of infection or illness with sexual activity, or with being gay or a drug user;
- acute and severe anxiety;
- emotional lability (moving quickly and unpredictably from tears to laughter and vice versa);
- sadness and morbid concern about the future, work, lover/spouse, family, health;
- suspicion about the actions and behaviour of staff/loved ones/helpers;
- relief at knowing what causes the recent illness.

In conjunction with these, Miller also cites a number of *behavioural reactions* to shock:

- crying – episodic and often unpredictable;
- anger and irritability – towards anybody, often "sparked off" by trivial and unimportant events, (may be physical and/or verbal)
- withdrawal – distancing from present issues and circumstances, reluctance to become involved in conversation, activities or plans for treatment;
- self-denigration – description of the self as "deserving this plague", "worthless", "unclean and dirty";
- checking the body for signs of further infection or physical deterioration;
- questioning – for reassurance, further information.

The following points need to be repeatedly emphasized:

(1) HIV infection is not AIDS. Prognosis vary, but every infected person should be encouraged to live a normal social and economic life unless AIDS-related symptoms do not permit this. Since normal living requires the support of others, those concerned may need regular counselling to anticipate and cope with new needs.

(2) A person who is HIV positive should take care of his/her general health. The presence of other infections, such as other sexually transmitted diseases or any illness will affect the immune response and may hasten the development of AIDS. The counsellor must stress the need to avoid exposure to illness as a measure to prolong life. The counsellor must explain how the risk of infections can be avoided through general home hygiene and the prevention of other sexually transmitted diseases, emphasizing the use of condoms and reducing the number of sexual partners.

(3) Spouses and partners will need support; telling them that HIV infection has been found is difficult, and considerable support for this may be needed from the counsellor. Bringing spouses or partners in for counselling to prevent transmission and, where indicated, testing is a frequent counselling goal.

(4) Spouses and partners must be protected against infection. Condoms should be recommended to prevent infection transmission and re-infection of the patient. The counsellor should stress the need for care in ensuring that the condoms are of good quality and intact. Latex condoms are much safer than animal-membrane condoms. *The proper and consistent use of condoms* should be stressed. The use of

condoms may not be acceptable in some cultures and countries. Objections to them, and the consequences of not using them, need to be discussed.

(5) Person who is HIV positive should not share their syringes, needles, or other skin-piercing instruments.

In summary after a positive test result, post-test counselling should:

- ensure that the person *understands* what a positive HIV test result means;
- discuss how they *feel* about being infected;
- provide *support* to help the person deal with these feelings;
- discuss their *plans* for the immediate future;
- establish a *relationship* with the person as a basis for future counselling;
- *schedule* appointments for medical evaluation and follow-up counselling;
- *counsel* partner(s) if possible; and
- *refer* the person to local community services if possible.

4.3 Guidelines on Prevention of Further Sexual Transmission of HIV

The following general guidelines are aimed at individuals or groups directly affected by an HIV-positive result. Counsellors can share them with the clients and their partners or give them as a hand-out for them to read and keep.

Recommendations to HIV-infected persons

(1) Inform former and current sexual partners about your HIV infection and recommend that they visit a testing centre or health-care provider for counselling and evaluation (including, if available, serological testing). If you are unable or unwilling to notify former and current sexual partners personally, request health workers or public health agencies to notify or help with notifying such partners.

(2) Inform potential sexual partners of your HIV infection and either decide to avoid sexual intercourse, rigorously restricting sexual contact to activities (e.g., hugging, caressing) that do not involve sharing of semen, vaginal and cervical secretions, or blood, or discuss the precautions that need to be taken to minimize the risk of HIV transmission from sexual activity(e.g., the use of condoms).

(3) If you both decide to engage in penetrative sexual intercourse, learn how to use condoms correctly, as consistent correct use will reduce the risk of HIV transmission.

(4) Strictly avoid sexual intercourse when you or your sexual partner has an infection or lesion in the genital, anal, or oral area and during menstruation.

(5) Avoid pregnancy. HIV-infected women who are pregnant should know about the great health risk to their unborn children and the potential health hazard to themselves, and be provided with counselling services. HIV-infected men should discuss the hazard of pregnancy with their partners.

(6) Do not share syringes, needles or other skin piercing instruments.

(7) Do not donate blood, plasma, body organs, or other tissues.

(8) Mothers should continue to breastfeed.

(3) Educate patients about HIV transmission and its prevention, including, as appropriate:

- the avoidance of partners at high risk for infection(e.g. users of intravenous drugs, commercial sex workers, men who have sex with commercial sex workers, persons who engage in other high risk sexual activities).

- instruction on the correct use of condoms.

(4) Offer HIV testing and counselling to people at increased risk of HIV infection.

(5) Find out what services and resources are available within the community so that people can be referred appropriately.

(6) Where resources and programmes exist, be prepared to provide additional support through counselling, peer groups, and other services for HIV-infected persons and their sexual partners, or at least refer them to public health or other medical facilities for such support.

(7) Urge the person to refer sexual contacts, and be prepared to fulfil your role in such referrals, including referring the contact to public health agencies when indicated.

(8) Assist HIV-infected and non-infected users of intravenous drugs to obtain treatment for their addiction and to avoid sharing needles and drug-injecting equipment.

(9) Inform HIV-infected women who are pregnant about the great health risk to their unborn child and the potential risk to themselves, and provide them with opportunities for counselling. Provide similar information and counselling to all HIV-infected women in the childbearing age group.

6.3 Precautions for Health Workers

The statements in this section about precautions for health workers are based on the recommendations for prevention of HIV transmission in health-care settings of the United States Centers for Disease Control[6].

All HIV counsellors should be aware of the nature of these precautions, and counsellors and health workers everywhere will need to recognize the obstacles to implementing them. For example, there may be no sterilization equipment, disposable syringes, aprons or gloves. Health workers must then find other ways of protecting those who care for people who are HIV-infected or have AIDS.

Blood and body-fluid precautions should be consistently used with all patients. (HIV has been isolated from blood, semen, vaginal secretion, saliva, tears, breast milk, cerebrospinal fluid, amniotic fluid, and urine, and is likely to be present in other body fluids, secretions and exretions. However, epidemiological evidence has implicated only blood, semen, vaginal secretions, and possibly breast milk in transmission.)

Every attempt should be made to use universal precautions in the care of all patients, especially those in emergency-care facilities, where the risk of direct contact with blood is increased and where a patient's HIV status is usually unknown.

All health workers should, when possible, routinely use barrier precautions to prevent skin and mucous-membrane exposure when contact with blood or other body fluids of any patient may occur. Gloves should be worn for touching the blood and body fluids, mucous membranes, or non-intact skin of all patients, for handling articles or surfaces soiled with blood or body fluids, and for performing venipuncture and other vascular access procedures. Gloves should be changed or washed after contact

with each patient. Masks and protective eyewear or face shields should be worn to prevent exposure of the mucous membranes of the mouth, nose, and eyes during procedures that are likely to release drops of blood or other body fluids. Gowns or aprons should be worn during procedures in which splashes of blood or other body fluids are likely.

Hands and other skin surfaces should be washed immediately and thoroughly if contaminated with blood or other body fluids. Hands should be washed after gloves are removed.

All health-care workers should take precautions to prevent injuries caused by needles, scapels and other sharp instruments or devices used during medical procedures, when cleaning used instruments, and during disposal of used needles. To prevent "needlestick" injuries, needles should not be manipulated by hand[7]. Proper disposal, must be assured for protection of health workers and the general public. Sterilization of re-usable syringes must be done between each injection.

Although saliva has not been implicated in HIV transmission, to minimize the need for emergency mouth-to-mouth resuscitation, mouthpieces, resuscitation bags, or other ventilation devices should be available for use in areas in which there is likely to be a need for resuscitation.

Health-care workers who have open lesions or weeping dermatitis should refrain from all direct care and from handling patient-care equipment until the condition resolves.

In many places, but particularly in developing countries, supplies of all kinds are hard to come by at best. Conforming to the recommendations is quite difficult when disposable instruments and materials, and equipment or fuel for sterilization, are often unavailable or in short supply. Counsellors and all health workers should take the recommended precautions whenever possible and used alternative procedures only when the necessary supplies are not available. Discussions among health workers on what alternative precautions may be used – given the materials that are available – will be useful. Such precautions will vary from place to place and will depend on what supplies are available.

Glossary[1]

Client

The person seeking or receiving HIV counselling and/or testing. In the case of a child or other person unable to consent to testing on his/her own behalf, the client is the parent or other adult with the ethical and legal competence to do so.

Counselling

A confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour.

Pre-test Counselling

Dialogue between a client and a care provider aimed at discussing the HIV test and the possible implications of knowing one's HIV serostatus, which leads to an informed decision to take or not take the test.

Post-test Counselling

Dialogue between a client and a care provider aimed at discussing the HIV test result and providing appropriate information, support and referral, and at encouraging risk-reduction behaviours.

Testing

(1) Laboratory testing, i.e., application of an assay (e.g. ELISA) for laboratory markers of HIV infection such as HIV antigen or antibodies. The assay may be used in order to screen blood for transfusion, or organs or tissue for transplantation (see screening), or in order to test an individual (see testing (2)).

(2) More broadly, the testing of individuals with the intention to determine their HIV infection status. All testing in this sense can be categorized according to three sets of criteria:

(a) client-initiated, health care provider-initiated, or required by a third party for other than health purposes;
(b) with or without informed consent; and
(c) anonymous, confidential, or non-confidential. These terms are defined below.

Client-initiated testing

HIV testing requested by a client on his/her own initiative.

Health Care Provider-initiated Testing

HIV testing initiated by the client's health care worker.

Testing Initiated or Required by a Third Party for Other than Health Purposes

HIV testing for other purposes, such as immigration, employment or insurance.

Testing without Informed Consent	HIV testing in which informed consent, as defined above, has not been requested and given.
Mandatory Testing	HIV testing without informed consent which the individual is compelled to undergo. The term refers both to situations in which the individual clearly has no alternative – as when prisoners are tested involuntarily – and to situations in which refusal of testing is not realistic or would cause the individual undue hardship, as when HIV testing is required prior to employment or marriage.
Anonymous Testing	HIV testing in which the blood sample and test result are identified only by code, not by name, with no personal identifiers to link the sample to the donor source.
Linked Anonymous Testing	HIV testing in which the code is known only to the client.
Unlinked Anonymous Testing	HIV testing (e.g., for surveillance purposes) after prior removal of all personal identifiers, so that retrospective identification is impossible
Confidential Testing	HIV testing in which only the client and the health professionals involved in the client's direct care know that the test was performed and have access to the test results. This information is not furnished under any circumstances to other health care providers, health authorities, employers, insurers, schools or other third parties without the patient's explicit consent.
Non-confidntial Testing	HIV testing conducted neither anonymously nor confidentially.
Voluntary Testing	Anonymous or confidential testing initiated by either the client or his/her health care provider and performed with the client's informed consent.
Screening	The systematic laboratory testing of donated blood, blood products, tissue (including sperm) and organs for the purpose of preventing HIV transmission to the recipients. Other specimens, such as saliva, may also be used.

•"Routine testing" is sometimes used to mean the HIV testing of individuals without their knowledge or unless they specifically refuse such testing. Examples are routine testing policies applied by hospitals to patients, and sometimes applied to people attending antenatal or STD clinics. This term should not be used because it does not specify whether informed consent is requested and granted.

SUMMARY

Many incorrect ideas exist about HIV antibody testing, often wrongly referred to as "the AIDS test". The counsellor must therefore ensure that the client understands what a positive or negative result means. Pre-test counselling must enable people to decide for themselves whether or not to be tested, and must be based on an assessment of the client's risk of exposure to HIV, understanding of HIV/AIDS, and previous experience in dealing with crisis. The counsellor must stress that no test can tell whether someone has, or will develop, AIDS. After a negative test result, it must be pointed out that a "window period" of at least three months must elapse before this can be taken to mean that infection is not present. After a positive result, the client must first be given time to absorb the news, deal with his/her emotional reactions, and then given a factual explanation of what it means, after which support needs to be provided. The counsellor must always stress the individual's responsibility to change his/her behaviour so as to avoid transmission, in view of the life-long nature of the infection. The use of condoms should be recommended but it may not be acceptable in some cultures. After an equivocal test result with the ELISA test, it is usual to retest, again with ELISA, after which another test using ELISA of a different antigen type is necessary. Where the result remains indeterminate, the counsellor should advise the person to present for repeat testing after three months. There are some difficult issues that need to be resolved after taking into consideration the government policies, medical ethics and legal practices of the country. These concern compulsory testing, informed consent, confidentiality and official policies on further testing.

MODULE 7

PROBLEM-SOLVING COUNSELLING

MODULE 7

PROBLEM-SOLVING COUNSELLING

Objective: To enable the trainees to build skills in helping individuals and families solve problems and assess level of risk.

Time to complete the Module: 2 hours.

SUMMARY OF ACTIVITIES

(1) Presentation: Process of problem solving.
(2) Role plays.
(3) Storyboard: Living with HIV.
(4) Review Questions.

Activity 1: PRESENTATION: PROCESS OF PROBLEM-SOLVING (20 minutes)

The aim of this activity is to focus the attention of the trainees on the major essential steps in problem-solving. The steps to emphasize are:

- *identifying* the client's problem;
- clarifying what *options* are available;
- helping the client *choose* the best option;
- taking *action*.

The trainer tells the real story of a particular HIV-positive client whom he/she knows well. Change the name of the person so that he/she cannot be recognized from the story. At each point in this person's life, where he/she is confronted with a problem related to HIV (such as whether to tell his/her partner that he/she is HIV-positive; whether to disclose HIV status to his/her employer; whether to change work/name/place of residence; facing isolation in the community), pause and ask the trainees to write on a piece of paper what they think is the *client's real problem* at this time. Try to generate thinking on some possible options for this person at each point. Ask participants to think of the positive impact a counsellor might have at that point in the person's life.

By the end of the story, the trainees should have a clear understanding and appreciation of the link between how a client sees a problem and the eventual course of action he/she chooses.

Activity 2: **ROLE PLAYS** (1 hour)

This activity gives trainees the opportunity to practice the skills of problem-solving. During the activity, it is important that the trainer does not allow the counsellor to *advise* the client *until* the problem has been properly identified. Trainee-counsellors too often want to immediately offer advice, rather than moving through the stages of: problem identification, clarifying options, deciding on the most suitable option and then the action that needs to be taken.

The trainees form into 3 small groups. Only the person playing the role of the client is given the details of his/her role. The job of the person playing counsellor is to help the client identify what is the client's problem and help solve it. During the role plays, change the "counsellor" every 5 minutes, with each "counsellor" picking up and carrying on from where the previous "counsellor" stopped. Ask the observing group members to give their inputs or suggestions once the role play is over. Encourage as many members as possible to become the "counsellor" and to use the skills learnt in earlier sessions/modules.

If a group achieves the objective of the exercise quickly, give them another case to role play. Some cases have been listed here. The trainer can also develop other scenarios based on local examples that are known to him/her. Allow 45 minutes for the role plays.

At the end of the role plays, ask the trainees what they learnt and what they found difficult.

Activity 3: **STORYBOARD: LIVING WITH HIV** (25 minutes)

This activity is included to familiarize trainees with the ongoing/flowing nature of problem-solving counselling. For this activity, make copies of the attached drawing and cut each of the 4 illustrations/cartoons into separate squares, with one picture in each square. Divide the trainees into small groups. Give a set of the pictures to each small group and inform them that in each picture, someone is HIV positive. The group should agree which person is HIV positive and how the story develops. Ask them to then arrange the pictures in the sequence which shows what really happened, acccording to them.

Next, ask the groups to assess the level of risk seen in each picture and make a list of 3 problems that the HIV person might be experiencing at that stage. They also suggest who else can help the HIV positive person solve his/her problems.

This exercise now introduces the fact that whole families soon become involved with HIV and that a counsellor needs to be able to deal with families as well as individuals. The full group re-assembles and the trainer facilitates a short discussion on the sequence of the pictures seen by each sub-group and what the exercise highlighted for them. The trainer then rounds up the session by reminding the trainees of the 4 major steps in problem-solving (identification of problem, clarification of options, selection of best option, decision/implementation of action).

Activity 4: **REVIEW QUESTIONS** (15 minutes)

Trainees fill the worksheet at the close of the session. They form pairs and compare their replies with each other. The trainer observes and clarifies responses for those who seem confused or unsure.

WORKSHEET: REVIEW QUESTIONS

1. **List in the correct order the important steps a counsellor needs to use for problem solving.**

2. **Which step do *you* personally find most difficult for helping a client and how can you improve your skill for overcoming it?**

3. **What would have been the last thing you would have said to the client at the end of the role play counselling session in Activity 2?**

4. **List 3 probable feelings a client may experience as a problem-solving session ends.**

For Activity 2

ROLE PLAY 1

A 24-year old man addicted to heroin is currently unemployed. He not only steals articles from his house but also occasionally sells blood to pay for drugs. His mother knows about his injecting habit. She has always protected him and has managed to keep it a secret from his father (her husband).

One of the blood banks told him he must not donate blood anymore because he is HIV positive. He also begins to develop frequent illness.

His mother comes to know of the test result. She is nervous and wonders whether she should inform the father or not. She seeks assistance.

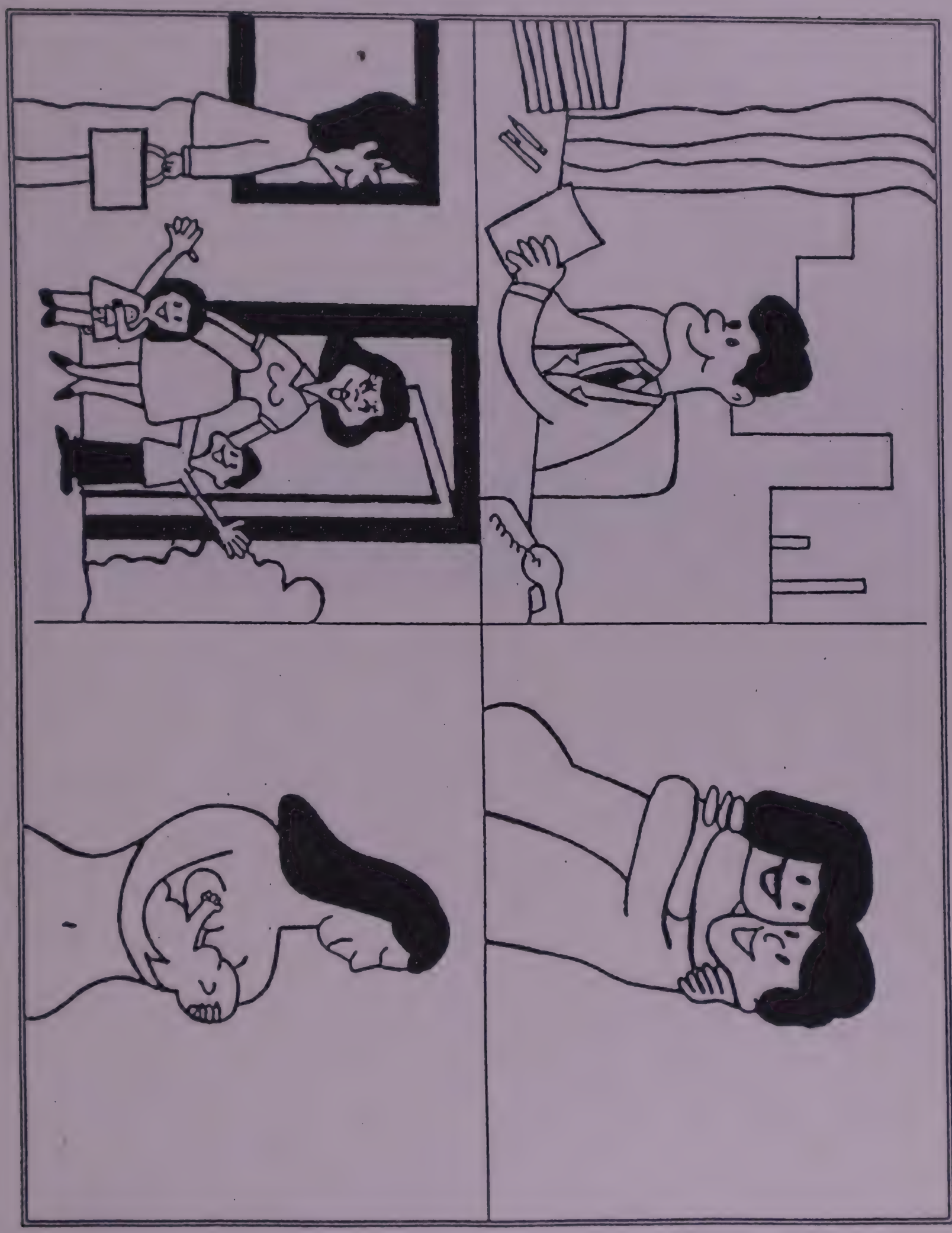
ROLE PLAY 2

A 23-year old housewife has two children and is pregnant with another child. Her husband currently works with the railways and stays at home, but previously he used to work as a migrant worker in a neighbouring district, sometimes being away for more than one year at a time. She has heard about AIDS and wonders whether she or her children are at risk. She goes to a counsellor for help.

ROLE PLAY 3

A 20-year old girl was notified that she was HIV positive after having worked for 2 years in a brothel. She was sacked at the same time and also not given any of the money that was owed to her by the madam of the brothel. She has no money in her pockets. Her brother is a truck driver and could find her work as a prostitute if she so desires. She walks into a clinic to talk with a counsellor.

DRAWING – *For Activity 3*



Supplementary Reading

PROBLEM-SOLVING AND CRISIS COUNSELLING

PROBLEM-SOLVING AND CRISIS COUNSELLING

1. PROBLEM-SOLVING COUNSELLING

Clients need a clear definition of their problems, whether they are at risk of, or have been found to have, HIV infection, or fear that they may have become infected. Learning the facts about transmission and the nature of HIV infection will often be a starting-point for examining the problem and how to deal with it.

The person concerned must have factual information on which to base decisions. The counsellor, too, needs certain information about the client, e.g., the number of sexual partners, the use of needles, blood transfusion history.

Problem-solving counselling relies very heavily at first on emotional support and empathy. While the "problem" of personal HIV infection cannot be solved, it and its present consequences can be clearly defined, so that alternative courses of action can be worked out, and plans made for living the rest of life to the full. Despite the ominous outlook for those with HIV, clients can be helped through the crisis to the point of being able to solve problems once more and handle day-to-day difficulties related to being HIV-infected, maintaining health, and dealing with the reactions of others.

The problem-solving approach is used to help clients:

(1) understand the nature of the illness;

(2) think through the impact of the disease on daily living;

(3) acquire or strengthen personal skills for dealing with the crisis; and

(4) change behaviour to protect themselves and others.

Crisis counselling and problem-solving counselling often take place at the same time. A client feels able to manage the crisis depending on the degree to which the problem becomes comprehensible. Crisis counselling focuses directly on the present; problem-solving counselling is concerned with learning about the client and planning together the prevention of infection, or the management of illness, methods of coping with anxiety and fear, and medical care.

In problem-solving counselling, the counsellor :

- demonstrates concern and support by taking the client's definition of the problem seriously;
- explores all aspects of the problem;
- brings out into the open and discusses the client's feelings and fears;
- discusses the action the client has already taken;
- discusses the personal and other resources available or needed;
- by realistic reassurance, shows how normal and predictable the client's reactions are;
- explains accurately the protective action the client will need to take; and
- helps the client establish a plan of action.

Some basic principles of crisis counselling are:

- Stay in the "here and now", i.e., focus on the client's expression of feelings and anxieties. It is the time to talk not about past history or behaviour, but about present feelings.
- Clarify what the client regards as the crisis.
- Determine the client's feelings about the event or information.
- Check – by means of questions and observations – for feelings of helplessness, hopelessness, and loss of control.
- Observe whether the client shows signs of strength and of the ability to make decisions even in a crisis, or gives an impression of paralysis and lack of resolution.
- Give a brief assessment of the position and show that the seriousness of the crisis feelings is appreciated.
- Ascertain what the client regards as the most, as well as the least threatening, aspect of the crisis.
- Select one aspect on which to begin work, preferably involving a task that the client can accomplish with some support.
- Agree on what is to be done to resolve or ease the crisis.

The counsellor may need to give some information repeatedly, perhaps because the client is using denial as a defence mechanism or is too distressed to understand what is being said.

SUMMARY

Problem-solving counselling enables the client to handle the day-to-day difficulties associated with being HIV-infected. The important elements of problem-solving counselling are: identifying problems, the clarification of options, selection of most suitable options, and the initiation of action. Crisis counselling is often required because of the serious implications of the infection. A crisis can be regarded as being made up of four elements: the blow, the recoil, withdrawal and acceptance. In a crisis, the counsellor's aim is to define the problem quickly and restore a sense of control.

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It would be unrealistic to expect that this Guide would help trainers produce fully fledged counsellors at the end of the training period.

Trainees would need to further acquire and refine their counselling skills under supervision and support.

5

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EDITORIAL REVIEW

Testing for HIV at home: what are the issues?

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AIDS 1996, 10:1455–1465

Keywords: HIV, home test, saliva, urine

Introduction

HIV, the virus that causes AIDS, was identified in 1983. Only 1 year later, in 1984, a reliable test for antibody to HIV was developed and became widely available in many parts of the world by 1985. The development of this test has enabled researchers to increase their understand of HIV infection and AIDS, allowed health care workers to diagnose HIV infection in patients, and has given individuals the choice of knowing whether they are infected with HIV.

In the past 10 years, much scientific, experiential and anecdotal information on the voluntary use of laboratory-based serological testing for HIV has been collected, helping us to understand the reasons why people seek an HIV test, and also the possible obstacles of doing so. In most industrialized countries HIV testing has been widely available and a high proportion of the population has undergone testing [1–3]. The main reasons for voluntary HIV testing are blood donation, testing during pregnancy, to find out one's HIV status, and routine screening at sexually transmitted disease clinics. Other reasons include hospitalization, insurance, military enrolment, or immigration. However, there is evidence that even where HIV testing is made widely available individuals may refuse to be tested even if they have engaged in some risky behaviour [4], and that people who seek HIV testing may not return to collect their results [5,6]. Possible obstacles to seeking a test or coming back to collect test results include the misperception of the risk of HIV infection, privacy concerns (confidentiality, anonymity), perceived inability to cope with the test result and fear of stigmatization and rejection if found positive [7].

The main reasons for which widespread use of voluntary HIV testing has been advocated are individual benefits (knowledge of one's serostatus, in particular after potential exposure to HIV, early access to clinical care, planning for the future and a more informed choice concerning personal preventive strategies), decreased pressure on blood transfusion services, including self-deferral of persons at risk of HIV infection, and prevention of the further spread of HIV. Although nobody would deny the potential benefits of HIV testing for the individual, its public health impact remains a highly contentious issue. Overall, the evidence for the impact of HIV testing in bringing about behaviour change is mixed [8]. It has been shown that voluntary counselling and testing (VCT) can enhance safer sexual behaviour in discordant couples if both partners are tested and counselled [9,10]. On a public health scale, however, little change in behaviour has been documented in heterosexuals if they are tested alone (i.e., without their partners) [11–14]. In addition, some studies have documented an increase in risky behaviours after testing in HIV-negative persons [15]. The major problem is that there are very few reliable data from epidemiologically sound studies, and that there may be many confounding variables, such as the quality of the counselling provided with the testing, the initial risk perception of the individual, the attitude of family members or the social environment.

Thus, after 10 years of experience with HIV testing mainly in industrialized countries, and to an increasing extent in urban areas of developing countries, we are unable to draw definite conclusions about the role of HIV testing in controlling the further spread of HIV. The main argument for making HIV tests widely available and accessible remains that every person should have access to information about her own health status in order to make informed personal choices about HIV prevention and care. In line with this argument, HIV home testing has been advocated as an important means of providing better access to testing to a greater number of people.

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The purpose of this article is to review the technical performance of home tests that are currently or will soon be available for use, to examine policies with regard to the licensing of these new tests in industrialized countries, and to discuss potential benefits and pitfalls of this new technology with particular reference to its use in developing countries.

Technical state of the art on HIV home collection and home self-tests

The term 'HIV home testing' creates confusion because it is used to refer to two different types of test. 'HIV home testing' is immediately associated with 'do-it-yourself tests', but in fact it usually refers to collection of specimens at home [16]. In this review, we will use the term 'home collection' to refer to a system whereby the individual collects her/his sample at home by means of a home collection kit. The specimen with an identification number is then mailed to a testing facility, and approximately 7 days later the individual can call for the result. According to the test result, appropriate counselling is given either by voice mail (negative result) or person-to-person (positive result). This system is also known as 'home access testing' [17]. We will use the term 'home self-test' for a testing system that can be carried out entirely at home, without involvement of a third party [18]. For obvious reasons, counselling is not an integral part of this system. Although the self-test instructions may urge the user to contact health care facilities in case of a positive result, it is left to his/her initiative to do so. Where we refer to both systems simultaneously we will use the term 'home testing'.

Specimen collection

The imminent evolution, or perhaps we should say revolution, in the field of HIV testing is the result of the development of technology allowing body fluids other than serum or plasma to be used for the detection of HIV antibodies. Traditionally, HIV tests have been based on the detection of HIV antibodies in serum/plasma derived from whole blood collected by venipuncture, and hence require trained health care workers for collection and laboratory facilities for testing.

The use of body fluids other than blood, such as saliva or urine, for detecting antibodies to HIV are attractive alternatives for several reasons. Saliva specimens can be collected or self-collected virtually anywhere: in the home, on the street, in bars. Furthermore, non-invasive sampling methods are safer for the subject and for the health care worker (there is no danger of contamination through unsterilized syringes or needle-stick injuries) [19,20]. There are similar advantages in the use of urine specimens, and the infectivity of both body fluids seems to be very low [21–23].

Whole saliva can be collected by dribbling into a receptacle or with the aid of a commercially available oral fluid device (Table 1). These devices usually consist of cotton-wool pads on a stick or sponge foam roll that has to be placed under the tongue, rubbed between gums and the cheek or gently chewed upon [24,25]. Mortimer and Parry [25], reported that approximately 5% of the saliva specimens received in their laboratory were inadequate in volume or composition. In order to guarantee an adequate specimen, clear instructions about the positioning of the device in the mouth, contact time, and prompt testing or mailing of the used device to the testing facilities must be provided. It is crucial that the sample is tested immediately, kept cool or is immersed in an appropriate buffer medium to prevent the decay of HIV antibody by enzymes present in the sample during transport [26]. However, some of the buffer mediums are not compatible with all HIV tests and information about this should be included in the insert (Dr J. Russi, personal communication, 1995).

As for oral fluid, urine specimens can also be kept for a short period at +4°C or should be stored for longer periods at −20°C or colder [25,27,28]. However, it may be preferable to use fresh urine samples for testing, because repeated freezing and thawing might affect the test result [29,30].

Another sampling method which has proved its usefulness for several diagnostic analyses is the collection of dried blood spots (DBS) on filter paper [31]. In general, capillary blood is obtained by finger prick (adults) or a heel prick (neonates) using a spring-loaded lance [32,33]. Quantities sufficient to saturate at least two spots (diameter 6–10 mm) on absorbent filter paper should be obtained, air dried, and stored in a sealable plastic bag with a desiccant for mailing [34]. DBS are easily transported by mail and can be economically stored for several months without loss of antibody reactivity [34,35].

As a finger prick is slightly painful, people tend to favour providing a saliva specimen [33,36]. In one study, only 69% of injecting drug users (IDU) agreed to provide finger prick specimens compared with 83.3% who agreed to provide oral fluid specimens [37]. A European multicentre study reported that 42 female sex workers who had refused to give blood agreed to provide oral fluid for testing [38]. The option to supply an oral fluid specimen substantially improves the coverage rate, but urine specimens and DBS collected for other purposes could also be used for unlinked HIV testing [32,37,39].

The above sampling methods can be applied in virtually all circumstances. They seem to guarantee a higher compliance and make HIV testing acceptable to population groups that have objections, on religious or other grounds, to blood being drawn [35,36,40,41].

Table 1. Performance of HIV assays using saliva specimens compared with the standard using serum or plasma specimens.

Assay (manufacturer)	Collection device	Total	HIV-positives [n(%)]	Sensitivity (%)	Specificity (%)	Country	Reference
ELISA							
HIV-1 2nd generation EIA (Abbott, North Chicago, Illinois, USA)	Orasure	503	135 (26.8)	98.5	100	Mexico	[47]
Recombinant HIV-1/2 EIA (Abbott)	Whole saliva	627	184 (29.4)	82.1	100	UK	[27]
	Salivette	100	50 (50)	88	100		[50]
Recombinant HIV-1/2 3rd generation (Abbott)	Orasure	285	38 (13.3)	92.7	100	Tanzania	[48]
Recombigen HIV-1 EIA (Cambridge Biotech, Galway, Eire)	Whole saliva	177	103 (58.2)	98.1	100		[37]
	OmniSal	475	74 (15.6)	90.5	99.5	Thailand	[26]
Vironostika HIV mixt (Organon Teknica, Boxtel, The Netherlands)	Whole saliva	194	79 (40.7)	100	100	The Netherlands	[51]
	Salivette	62	22 (35.5)	32	100		[51]
Gacelisa HIV1+2 (Murex, Dartford, England, UK)	Salivette	100	50 (50)	98	100	Australia	[50]
	OmniSal	474	74 (15.6)	94.6	99.5	Vancouver (Thailand)	[26]
	Whole saliva	129	24 (18.6)	92.0	100	Benin	[52]
	Whole saliva	570	237 (40.3)	98.7	98.5	Rwanda	NP[§]
	OmniSal	570	237 (40.3)	98.7	97.9	Rwanda	NP[§]
	Whole saliva	611	356 (57.5)	98.9	99.6	Burundi	NP[§]
	OmniSal	611	356 (57.5)	97.8	97.2	Burundi	NP[§]
	Orasure	448	140 (31.2)	99.3	100	Uruguay	NP[¶]
	OmniSal	448	140 (31.2)	100	100	Uruguay	NP[¶]
Simple rapid assays							
Serodia HIV (Fujirebio, Tokyo, Japan)	Whole saliva	600	179 (29.8)	97.8	84.1	UK	[27]
	Whole saliva	129	24 (18.6)	66	100	Benin	[52]
Testpack HIV-1/HIV-2* (Abbott)	Orasure	288	44 (14.3)	100	100	Tanzania	[48]
	OmniSal	448	140 (31.2)	97.9	100	Uruguay	NP[¶]
	Orasure	448	140 (31.2)	96.4	100	Uruguay	NP[¶]
SalivaCard* (Trinity Biotech, Dublin, Eire)	Orapette	615	115 (18.7)[†]	100	99.8	USA/Peru/ Côte d'Ivoire	NP[‡]
SUDS HIV-1* (Murex)	Salivette	142	92 (64.8)	97.8	96.0	UK	NP
	Orasure	266	35 (13.2)	97.2	100	Tanzania	48

Collection devices: Orasure (Epitope, Beaverton, Oregon, USA); OmniSal (SDS, Vancouver, Washington, USA); Orapette (Trinity Biotech); Salivette (Sarstedt, Leicester, England, UK). *Could potentially be used as home self-test. [†]Includes five HIV-2-positive specimens. [‡]External report provided by manufacturer. [§]Dr P. Kabutira, personal communication, 1996; [¶]Dr J. Russi, personal communication, 1996. ELISA, Enzyme-linked immunosorbent assay; EIA, enzyme immunoassay; NP, not published.

Assays

Until recently, the performance of HIV tests, even those using body fluids other than serum or plasma, were still confined to a laboratory setting. Today, the combination of easy and safe, non-invasive sample collection (saliva, urine or capillary blood) together with a simple, rapid, non-instrumental HIV test have made home collection and home self-tests for HIV a practical reality. However, there is concern about the intrinsic sensitivities and specificities of these assays when using non-conventional specimens. Another cause for concern is the reliability of these tests when performed and interpreted by lay persons.

The main technical problem is that the immunoglobulin (Ig) A and IgG antibody levels in saliva and urine are considerably lower than those in serum or plasma [25,29,42]. It has been shown that a minimum IgG concentration of 0.1 mg/l in oral fluid is necessary for reliable detection of HIV antibodies [43]. To compensate for this fact, test procedures of commercial test kits intended for serum and plasma were modified, usually by increasing the added sample volume or by concentrating the sample [24,25,44]. Another approach was the development of IgG capture assays, which first bind the total IgG fraction and subsequently detect the HIV-specific antibodies [45,46].

Several studies have been conducted to compare the results obtained using saliva with those using serum, and many different collection devices have been evaluated [26,27,33,40,47–58]. The majority of the studies based on oral fluid reported sensitivities and specificities in the range of 95–100% and 98–100%, respectively (Table 1).

Table 2. Performance of HIV assays using urine and dried blood spot specimens (DBS) compared with the standard using serum or plasma specimens.

Assay (manufacturer)	Total	HIV-positives (%)	Sensitivity (%)	Specificity (%)	Country	Reference
Urine						
Recombinant HIV-1/2 3rd generation EIA (Abbott)	286	34 (11.9)	77.3	100	Tanzania	[48]
Calypte HIV urine EIA (Calypte Biomedical, Berkely, California, USA)	916	916 (100)	98.7		USA	NP*
GACELISA HIV-1/2 (Murex)	333	84 (25.2)	98.8	99.2	Malawi	[21]
	75	32 (42.7)	96.9	100	Côte d'Ivoire	[56]
	110	55 (50)	98.2	100	Thailand	[57]
	90	42 (46.7)	88.1	97.9	Tanzania	[58]
GACPAT (Murex)	336	86 (25.6)	96.5	98.8	Malawi	[21]
	75	32 (42.7)	100	88.4	Côte d'Ivoire	[56]
	90	42 (46.7)	100	97.9	Tanzania	[58]
Testpack HIV-1 + HIV-2† (Abbott)	284	43 (15.1)	97.7	100	Tanzania	[48]
SUDS HIV-1† (Murex)	241	23 (9.5)	69.7	99.0	Tanzania	[48]
DBS or whole blood						
Vironostika HIV EIA (Vironostika, Boxtel, The Netherlands)	1020	–		99.7	USA	[70]
Abbott HIV EIA	1020	–		100	USA	[70]
GACELISA HIV-1/2 (Murex)	110	55 (50)	100	98.2	Thailand	[57]
	40	34 (85)	100	100	Italy	[69]
GACPAT HIV-1+2 (Murex)	40	34 (85)	100	100	Italy	[69]
Serodia HIV (Fujirebio)	40	34 (85)	100	83.3	Italy	[69]
SimpliRed† (Agen, Acacia Ridge, Australia)	1800	251 (13.9)	99.6	99.6	Thailand	[68]

*External report provided by company. †Could potentially be used as home self-test. EIA, enzyme immunoassay; NP, not published; WHO, World Health Organization.

A few studies using traditional HIV tests show significantly lower indices [27,50,52], whereas the results obtained with the IgG antibody capture enzyme-linked immunosorbent assay (GACELISA; Murex) and IgG antibody capture particle adherence test (GACPAT; Murex), which first concentrate the IgG fraction from the sample, are generally excellent [26,33,50,52]. No significant difference has been shown between direct dribbling and the Orasure (Epitope) or Omni-Sal (SDS) device (Dr P. Kabutura and Dr J. Russi, personal communications, 1996), although one study has reported poor results when using the Salivette device (Sarstedt) [51]. Dental problems do not seem to have adverse effects on the test results [59].

Few data are available for assays which can be potentially used as home self-test, such as Testpack HIV-1/2 (Abbott, Delkenheim, Germany), HIV SalivaCard (Trinity Biotech) and SUDS HIV-1 (Murex) (Table 1). The HIVSpot HIV-1+2 (Genelabs, Singapore) gave negative reactions on all saliva specimens collected from 100 known HIV-seropositive individuals [49].

The data presented here were obtained under optimal conditions by trained technicians and may not reflect a real-life situation. The accuracy of simple rapid tests that require subjective interpretation is closely linked with training. Non-trained operators such as lay persons can easily misinterpret test results [60]. Kit inserts from strongly promoted home self-tests, such as the HIV Ana-Sal test (Americare Biologicals, Miami, Florida, USA), OraScreen HIV rapid test (Beacon, Foster City, California, USA) and K-Stat HIV test (Kenlor Industries, Santa Ana, California, USA), claim high reliability, although virtually no external data are available. It is clear that these statements should be validated by independent studies.

The sensitivity and specificity of various methods using urine specimens had ranges of 77–100% and 69.7–100%, respectively (Table 2) [21,48,56–58,61]. Similar to the oral fluid data, the performance of the IgG capture assays was often better than the conventional tests, although one study showed poor results with the GACELISA [58], and another with the GACPAT test [56]. Two studies reported false-positive results in urine samples from IDU [61] and from patients with urogenital diseases (11.8%), diabetes mellitus (20%) and autoimmune diseases (7.3%), and in pregnant women [62].

The sensitivity data for DBS were comparable with those for oral fluid, and ranged from 98.8 to 100% [57,63–72]. Observed false positivity rates with ELISA using DBS was as high as 45% compared with serum, whereas 9% showed indeterminate Western blot results [66]. These data may provide an indication of what can be expected from using these tests in low prevalence populations. In addition, a low sensitivity of the DBS technology has been reported for HIV-2 infection [67]. The above data were obtained with eluates of DBS and

conventional HIV test kits, except for the SimpliRed assay (Agen), which is a red blood cell agglutination test [68]. At present, there are new tests based on immunochromatographic flow technology which can be performed on just one drop of blood. Preliminary studies seem to yield promising results (Dr S. Mboup, Dr A. Pearson and Dr D. Barnes, personal communication, 1996).

As for all HIV testing, laboratory performance assessments are crucial for the validity of the results and initial reactive tests need to be confirmed [30]. This can be done by obtaining a serum sample for conventional confirmation from those individuals found to be reactive. However, it would be more convenient if the non-serum specimen could be used to confirm the initial result. Unfortunately, confirmation of positive screening results using non-serum/plasma specimens cannot always be successfully achieved [25,28,55,73,74]. In comparison with serum samples, Western blot tests fail to detect antibodies to all or certain viral proteins resulting in false-negative or indeterminate results [28]. In addition, reactivity towards all viral protein bands on Western blot are generally weaker when using oral fluid, urine or DBS specimens [37,40,44,51,55,70]. Hence, Western blot criteria may need revision for non-serum/plasma samples [37]. Alternatively, confirmation could be obtained by testing with a second assay that is also suitable for these specimens. Obviously, this strategy should be thoroughly validated against the conventional standard before implementation.

At present, the slightly lower sensitivity and difficulty in confirming a positive result remain the major drawbacks of the non-serum/plasma specimens. The level of sensitivity currently observed with non-serum/plasma specimens would be of concern when used for diagnostic purposes, but is acceptable for surveillance programmes. For example, neonatal DBS have been successfully used for nationwide surveys in several countries to estimate the seroprevalence among child-bearing women [63–67,73,75]. Several studies have demonstrated that oral fluid can be used successfully for unlinked anonymous HIV antibody testing, especially for otherwise difficult to reach population groups such as sex workers and IDU [26,27,33,36]. In addition, urine specimens collected for other purposes can be used for unlinked testing [39].

Current regulatory policies with regard to home testing

Many countries have agencies or legislation that regulate the licensing of drugs, medical devices and biological products such as HIV-related diagnostic tests. Countries that do not have such agencies rely on decisions made by regulatory bodies in other countries before giving permission for the marketing of certain test kits. To be on the safe side, some governments only allow the sale of diagnostic products, including HIV test kits, which have been approved in the country of production.

The aim of these regulations is to ensure safety in terms of production and clinical use of the kits, and efficacy in terms of sensitivity, specificity and reproducibility in the intended use setting.

Depending on the intended use — blood donor screening, surveillance or diagnosis — the regulations are more or less strict. For example, in the United States there is a lot-by-lot release of HIV tests kits that are approved for blood donor screening; in France there is a clear distinction between first-line (screening) and second-line (supplemental) test kits. Until recently, only HIV test kits using conventional serum or plasma for the detection of HIV antibodies were approved; other kits were restricted to research purposes. In addition, all aspects of HIV testing, including specimen collection, were performed under the supervision of trained health care workers.

On 14 May 1996, the US Food and Drug Administration (FDA) approved the first HIV testing system not entirely linked to the medical setting [76]. At least two other companies have also applied for a FDA licence of their HIV home collection testing systems.

The licensed Confide HIV Testing Service (Direct Access Diagnostics, Bridgewater, New Jersey, USA) is comprised of three integrated components: an over-the-counter home blood-collection kit, HIV-1 antibody testing at a certified laboratory, and a test result centre that provides test results, counselling and referral anonymously.

The home collection kit, which can be bought at a pharmacy or ordered by mail, contains a pre-test counselling booklet, a step-by-step instruction guide, the collection material and a protective envelope. The user takes a finger prick blood sample and places it onto the designated areas of the test card. The test card is pre-coded with a unique personal identification number (PIN code) assigned to each kit. The specimen is then mailed to a testing facility, and approximately 7 days later the individual can call for the result. According to the test result, appropriate counselling is given either by voice mail (negative result) or person-to-person (positive or inconclusive result). All components of the HIV home testing service are subjected to several regulations, which are closely monitored by the FDA. Both the testing and counselling facilities need annual accreditation and HIV testing procedures have to comply with FDA regulations.

The United States is also the only country where an oral fluid test system has been approved for initial diagnosis of HIV infection [77,78], although oral fluid tests have been used by other countries for surveillance purposes.

Most European countries have reservations about saliva tests for diagnostic purposes, because their performance is still inferior to that of the conventional specimens and their sensitivity for seroconversion specimens is as yet

unknown. Agencies have regarded test sensitivity as the most important issue when granting approval for HIV tests.

Several governments (Australia, Austria, France, Germany, Japan, The Netherlands, Switzerland, United Kingdom) have stated that diagnostic tests for determination of the individual HIV serostatus should not be used by the public without pre- and post-test counselling — in other words, testing should be undertaken with medical support [79,80].

It is currently prohibited by legislation in some countries (United Kingdom, Austria) to sell or supply HIV test kits or any component part of such a kit to a member of the public. However, times are changing and as the United States has now approved over-the-counter home specimen-collection kits other countries might follow in the future. No country envisages the approval of over-the-counter home self-test kits for HIV as yet.

Nevertheless, since the technology exists, manufacturers of these products will seek markets in other parts of the world where regulations are less strict. At least one company is offering a home self-test in the United States, which can be ordered with a credit card or a cheque payable to a PO box offshore. Manufacturers of certain HIV home self-tests include misleading statements in their promotional material claiming that their products are approved by the World Health Organization (WHO) or FDA; these statements are incorrect as the tests have not been evaluated by WHO and applications to the FDA for licences have not been made (unpublished data).

The current reluctance of several governments of industrialized countries to approve HIV home collection and home self-test kits for open marketing may be due to fear that the potentially negative consequences of this new technology could be more important than its positive effects. We would therefore like to briefly explore the arguments being used by proponents and opponents of home testing.

Potential benefits and pitfalls of home testing

The central argument for HIV home testing is that it would considerably increase the number of people who have access to and may use an HIV test. To our knowledge there is only one study that provides some insight into the potential demand for home collection HIV testing [16]. Twenty-nine per cent of adults interviewed during a national household survey in the United States said they were likely to use a home collection device for testing, and 22% said they would prefer this method to clinic-based VCT. Persons with less education, lower incomes, of non-Caucasian origin and who did not know where to go for an HIV test were more likely to say they would use home collection testing than the other groups. However, respondents were not informed about the probable price to pay for the test (estimated at US$ 30–40), and were not asked about the reasons for preferring home collection testing. In addition, no questions were asked about the intended timing of testing, in particular in relation to past or present risk behaviour. There are no similar data on the potential demand for home self-testing. An important reason for preferring home testing over laboratory-based testing may be a greater guarantee of confidentiality and anonymity. In addition, persons would be able to use a home collection kit or do a self-test at their own convenience without any loss of working time, and home self-testing would also have the advantage of providing immediate results.

Proponents of HIV home testing have argued that the main benefits of increased access to and use of HIV tests would be earlier treatment, including avoidance of perinatal transmission by HIV-positive pregnant women [17], decreased costs in general and for the public services in particular, and decreased sexual transmission of HIV [18]. Early access to treatment based on early knowledge of HIV status will be of benefit to the individual if and where such services are available. Currently, few treatment options for asymptomatic HIV-infected persons are available in most developing countries, although this may change rapidly if inexpensive preventive therapies for tuberculosis, toxoplasmosis and other opportunistic infections are shown to be effective [81]. Cost of home testing is assumed to be lower than clinic-based testing, although no comparative data have been published. The main arguments are that HIV-negative persons would only need one test, performed at home, with little or no counselling, thus reducing human resource and overhead costs. In addition, persons would pay for at least the first test, thus reducing public sector cost in instances where governments provide HIV tests free of charge [82]. Finally, the decrease in sexual transmission is based on the assumption that the individual who finds out he or she is positive would supposedly not engage in unsafe behaviour, that the couple 'could screen each other for the presence of HIV antibodies and then act on the findings', or that one partner could 'quietly' screen the other [18]. As discussed in the introduction of this review there is little evidence that HIV testing, even when provided with counselling, results in the adoption of safer sexual behaviours that would have a public health impact on HIV transmission.

The potential risks of home testing have been discussed by the proponents as well as the opponents [17,82–85]. A number of issues relate to the accuracy of the tests, including their sensitivity, specificity and predictive value; quality of the test at the time of use depending not only on the manufacturer, but also on transport and storage at the sales point and at home; quality of the sample collected; understanding of the window period; and,

more generally, the level of education needed to correctly understand the testing procedure. For home self-tests there are additional issues such as errors of manipulation if performed by lay persons; interpretation of results and action to be taken for confirmatory testing. We have addressed most of these issues above, but would like to point out again the fact that the accuracy of the new generation of capillary blood, urine and saliva tests that could potentially be used as home self-tests has not yet been evaluated extensively, nor has their reliability been confirmed if performed by lay persons. Beyond these technical issues, there are two other major questions with regard to the risk of home testing. First, does testing without pretest and post-test counselling present a risk to the individual tested? Secondly, is there a greater risk of systematic abuse of HIV testing by third parties than with laboratory-based tests?

In order to guarantee the individual benefits from an HIV test, to reduce the fear and occurrence of the negative effects of testing, and to increase the possible public health benefits, counselling has been promoted as an essential element of voluntary testing [86]. Ideally, the counselling process should start before HIV testing occurs to discuss the need for testing, provide accurate information about HIV, clarify technical aspects of HIV testing, discuss past risk behaviours and risk-reduction strategies and help explore the implications of the test results, particularly if positive. Counselling after the test should provide emotional support, and help the person to find the most appropriate medical and social care. However, it has been shown that in many countries testing is performed without counselling, or counselling occurs only after the test results are known [3,87–89]. Proponents of home testing therefore argue that pretest counselling is not essential and that counselling after home collection or self-testing could be provided more efficiently through telephone contact, which would be cheaper and guarantee anonymity [90]. Persons who test positive would be advised to, or would take themselves, the initiative to contact appropriate health services. This scenario relies on access to a telecommunication system and some type of quality control of the counselling process. In addition, it is not clear who would provide this service and pay for it. If this is the responsibility of the test manufacturer, as has been suggested, the incentive to train, supervise and maintain qualified counsellors is limited if this is not to be linked to a periodical accreditation system. Anonymity will only be guaranteed until the HIV-positive person goes to a health service, which should occur upon receipt of a positive test result.

In most developing countries telephone counselling would be highly impractical for the majority of the population. This implies that access to face-to-face counselling services needs to be guaranteed to clarify possible misunderstandings about the significance of a positive test. Home testing may lead on the one hand to an increased number of false-positives, because positive results would tend to be taken at face value after the first home test. This might be a problem especially in low prevalence populations. On the other hand, an increased number of false-negatives may occur due to testing shortly after a risky behaviour without retesting after 3 months.

One of the major concerns voiced by opponents to home testing is the potential abuse by institutions — employers, insurance companies, police, border controls — and by sexual partners, in particular by men against women. Proponents have argued that the possibilities for abuse may not be very different from those already existing [17], and that an otherwise beneficial product should not be outlawed because it may be potentially abused [82]. There are at least two reasons why home testing would be more amenable to abuse than laboratory-based testing: it is easier to perform under coercion and there is less guarantee of confidentiality because the result is directly available in the home or by a telephone call. Home 'self' tests, which also provide an immediate result, could be used directly at border controls, by future employers and by sexual partners with little or no consent of the person tested. Given the level of persistent discrimination and stigmatization in many countries, this potential for abuse is worrisome.

Overall, the risks and potentially negative consequence of the home test should be expected to be much greater in situations where the powerless are not well protected by law and regulations, where the status of women is not equal to that of men, where quality control of medical devices and procedures is difficult, where regulations are not enforced, where literacy rates are low, and where health services are either scanty or difficult to access.

Can we learn lessons from other home tests?

As discussed above, the introduction of HIV home tests on the market may have positive as well as negative consequences. Before jumping to any conclusions about their danger or their usefulness, one should realise that this is nothing less than a revolution in the history of health and medicine. This would be the first time that an individual has ever had the ability to diagnose by himself a chronic, incurable and most probably fatal condition. The only other home self-test to detect a health condition (as opposed to monitoring an already diagnosed health condition, such as high blood pressure, diabetes) that has ever been used widely in developed countries is the pregnancy test. Although the consequences of a positive pregnancy test are quite different from those of a positive HIV test, it is useful to briefly review some of the lessons learned from the home use of pregnancy tests which have been available for almost 20 years. It should be noted that the scientific literature on home use of

pregnancy tests is extremely limited and no information could be found for developing countries. Over-the-counter pregnancy tests became available in 1976, but were only widely advertised in the United States in 1978. The FDA, after reviewing data on several of these tests, stated that they were reasonably accurate for preliminary check-ups (95–98% accuracy) if 'special care is used in testing and a number of variables are taken into account' [91]. The FDA also urged users to immediately visit a doctor after a positive reading. The main concerns were false-positives, false-negatives (ectopic pregnancies) and the assurance of proper medical care. In addition, the early generation of home pregnancy tests was criticized for being too complicated with ample opportunity for manipulation errors [92]. The arguments used against making home pregnancy tests widely available were inexperience of lay people in testing procedures, difficulty in evaluating false-positive or false-negative results and that a pelvic examination should supplement the test. Arguments in favour of home testing included their lower cost, desire of anonymity and possibly earlier diagnosis leading to better prenatal care [93]. After these initial debates about the pros and cons, no assessment of the use of pregnancy tests at home was apparently performed for a number of years.

In 1982, a US-based study investigating the prevalence of home pregnancy testing and user compliance found that about one-third of 144 pregnant women seeking advice in three different treatment settings had previously used a home pregnancy test [94]. The overall false-negative rate was 24.3%, and total compliance with test instructions was 32%. Test accuracy was directly related to the educational level of the user. In 1986, it was shown that accuracy of test results at home ranged from 46 to 89%, differing from the 97.4% average claimed by the manufacturers [95].

A further issue identified in these studies was failure to respect the 9-day waiting period after missed menses and to repeat an initially negative test [94–96]. Some women used the test as early as 6 days, thus considerably lowering its predictive value. This can in some ways be compared with the window period in HIV testing, which is even longer and makes it virtually impossible to detect an infection before several weeks after the potential exposure to HIV.

The reasons most frequently cited by a sample of college students for using a pregnancy tests at home were speed in obtaining results, confidentiality and convenience [97]. About one-half of the users had the results verified by a laboratory test. The study concluded that one of the most crucial limitations of self-testing is the knowledge and competence of the user.

As with HIV testing, the lower cost of self-testing has been one argument in favour of home pregnancy tests, but this has not been well documented. Among the sample of college students only 5% mentioned the cost as a primary reason for choosing the home test. The 1978 Consumer Report [92] showed that an office-based pregnancy test could be obtained without appointment at the same cost than a home test (US$ 5–15), and thus discouraged self-testing.

Although early access to prenatal care and positive behaviour change, such as reduction of tobacco or alcohol intake, have been advocated as potential benefits of home pregnancy testing, this has not been documented.

The evidence on reasons for using home pregnancy tests, their accuracy when used by lay persons, and the possible negative consequence of inaccurate results is therefore sketchy. The main lessons learned may be that a test result will be on average less accurate when the test is performed by a lay person, and that the user needs to be well educated to understand operating procedures, optimal timing of the test (latency period) and needs to have immediate access to health services for confirmation of test results and care. Many of the studies mentioned have raised doubts about the usefulness and comparative advantages and disadvantages of the home versus the laboratory-based pregnancy test. Although the testing technology has changed in the past years, making today's pregnancy tests simpler than the earlier tests, no new data have been published and the questions raised have apparently remained unanswered 10 years later.

Conclusions

The new testing technologies discussed in this review may have enormous merits and may in many ways change our approaches to the HIV epidemic. These tests could be used for testing in a VCT service to provide clients with an immediate indicative test result. In cases of positive primary test results, a blood sample can immediately be drawn to perform further testing for confirmation, making the whole system more client-friendly and probably more cost-effective. In addition, this approach may reduce the high drop-out rates currently witnessed in some settings after initial counselling and the collection of the blood sample. However, we need to acknowledge that many technical, psychological and social questions remain unanswered. Given the nature of HIV infection — lifelong, incurable and fatal — and the stigma attached to it, it would seem irresponsible to provide these new tests to lay persons for self-testing before answering at least some of the most essential questions, including the following:

(1) What is the intrinsic accuracy of the currently available HIV home collection and home self-tests?
(2) What is their reliability if used by lay persons, including timing of the test after risk behaviour?
(3) What is the probability that persons identifying

themselves as HIV-positive through home testing will not seek confirmatory testing, and what would be the consequences of such behaviour?

(4) How cost-effective is home collection or home self-testing compared with clinic-based testing?

(5) What is the demand for and acceptability of these tests in different sociocultural environments?

(6) What are the expressed needs and fears of potential users?

(7) What is the importance of providing counselling before and after the test? What are the consequences for the individual if counselling is not provided or not sought?

(8) How can post-test counselling be provided in low-resource settings, including quality assurance?

(9) What action will individuals take after receiving an HIV test result at home?

(10) What is the potential for abuse in different settings and how can it be prevented?

All these questions relate to both forms of home testing, home collection and home self-testing, but will need to be addressed separately in some instances. Relatively small-scale qualitative and quantitative research studies in settings where access to VCT services already exist may enable us to provide some answers. It will also be instructive to monitor the experience with the HIV home collection test system which has just been approved in the United States.

In addition, some minimum requirements that must be fulfilled for any tests proposed should be defined, including (1) any test marketed as a self-test must have an internal control mechanism which validates the test result; (2) no test should be marketed in another country before having been approved by the regulatory body of the country of production, as there is a real danger that tests of low quality are brought on the market in developing countries with weak or no regulatory bodies; and (3) clear guidelines must be provided with the test on how to confirm a positive result. Access to counselling, medical and social support services should be guaranteed. A legislative framework should be established to minimize the possibility for abuse.

This review of the current state of the art of home testing has revealed that, although technical knowledge on this new testing technology is relatively advanced, virtually no information exists on the potential impact wide spread availability of home tests would have on individuals, on population groups that are at higher risk of or more vulnerable to HIV infection, and on society at large. At present it is thus impossible for policy makers and planners to make an informed choice about the use of these tests. If we want to abide by the Hippocratic principle of '*primum non nocere*', it is essential that sound research on the questions raised be undertaken immediately in a variety of settings, including developing countries, and that decisions on the use of home collection and home self-tests by lay persons be based on the results.

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MATERIAL ON HIV/AIDS

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Rights and respect

Philly Lutaaya Initiative

People with HIV who have the courage to speak out publicly help to reduce the fear of AIDS.

Increasingly AIDS organisations and activists acknowledge that two very significant barriers to successful HIV prevention are discrimination and inequality. Fear and ignorance about AIDS have led to discrimination against people living with HIV and those assumed to be 'high risk' because of their lifestyle or sexual partners.

While HIV can affect anyone, people – especially women – who lack access to information or health services, and who have little choice about what they do sexually, are most vulnerable to HIV. If they test HIV positive or become sick, they are even more at risk of discrimination. Discrimination can mean being dismissed from work, refused health treatment and avoided or attacked.

One response to the epidemic has been to introduce measures which restrict the freedom of infected or vulnerable people. These traditional public health measures were used to control epidemics such as tuberculosis or syphilis. They were based on compulsory testing, isolation of those with the illness and treatment to prevent others from becoming infected. However, it has become clear that these measures have far too high a social and financial cost.

Policies of isolation and compulsory testing make it easier to blame certain groups of people. Therefore most people do not feel at risk and so do not take steps to prevent HIV. At the same time people need information but may be afraid to seek advice and support.

Many AIDS organisations and health services are now working in close partnership with people with HIV to respond to the epidemic more successfully.

Dr Juan Carlos de la Concepción, on page 5, describes how he and other HIV-positive people in Cuba worked with their government to change the policy of compulsory isolation. They did this because they felt that this policy was preventing the wider public from coming to terms with the realities of HIV and the need for safer sex.

'We don't fear the virus or even death so much as the way in which others treat us.' On page 4 activists from Uganda emphasise the importance of being open about HIV. This not only helps others personalise the risk, but also makes it easier for them to negotiate protected sex.

But individuals who feel safe enough to be open about their HIV status are in a tiny minority. In most countries, people still risk losing everything – home, job, children, friends and family. Continuing to work against discrimination and for people's human rights is a vital part of the fight against HIV.

THIS ISSUE

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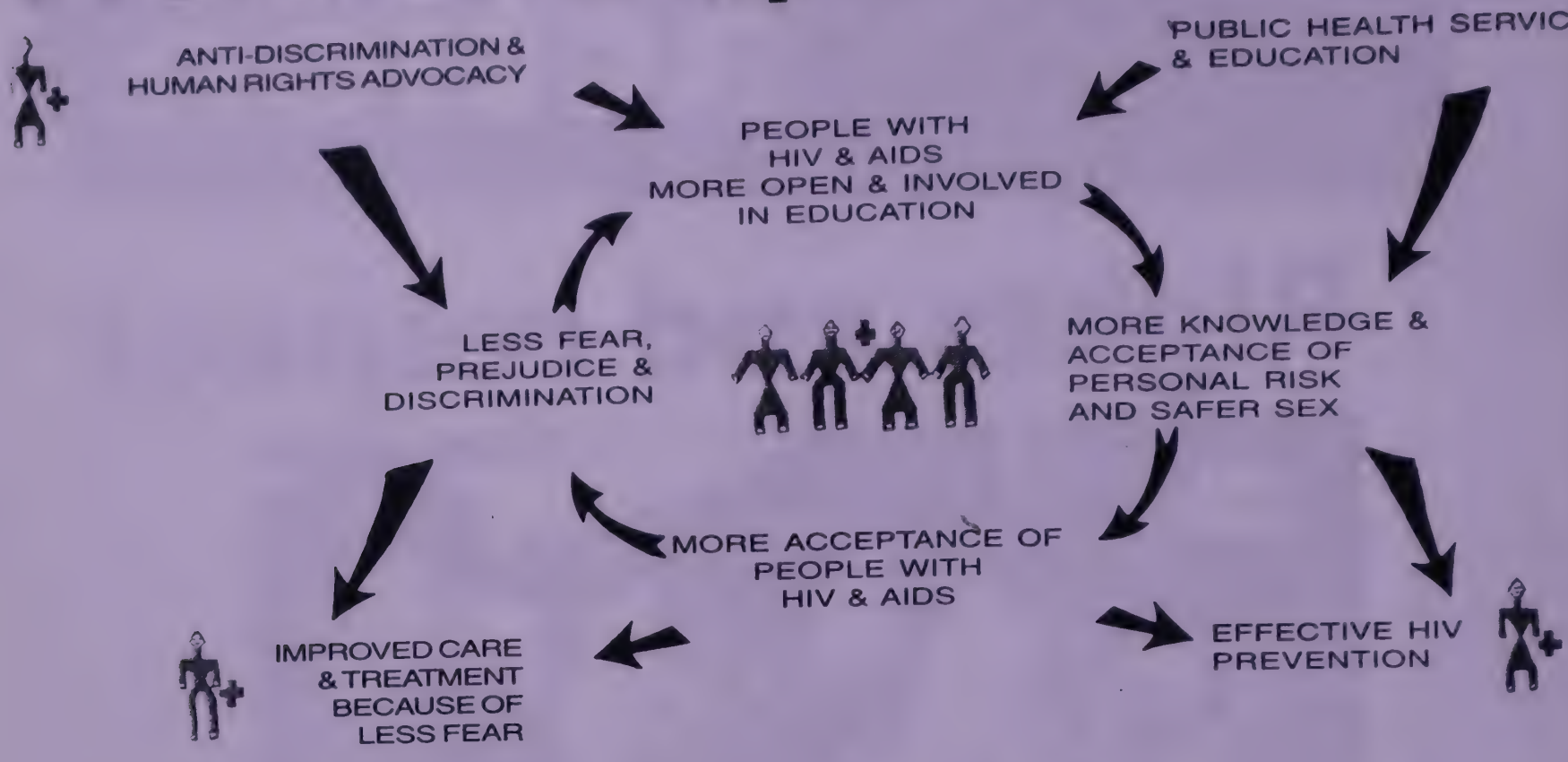
Prevent HIV, promote health



Some NGOs and individuals are using human rights approaches to challenge HIV-related discrimination. Respecting human rights means that all people are treated as equal in human worth and dignity, whoever they are. A Universal Declaration of Human Rights was agreed in 1948 and has since been signed by almost all nations. There are more recent international agreements on rights which are legally binding for nations who have signed them.

Of course, human rights are not only relevant to HIV – many people do not have access to minimum basic needs. But there are some forms of discrimination that directly affect people living with HIV or make some groups of people more vulnerable to infection.

APCASO members (Asia Pacific Network of AIDS Service Organisations) are developing a set of guidelines based on internationally recognised human rights and applying them to HIV. This is helping the NGOs to define and document HIV-related discrimination (see page 3). This makes it easier to campaign for policies and programmes that respect human rights, as well as provide better care and enable people to reduce their risk of HIV infection.

For more information about APCASO Human Rights Initiative contact APCASO, Kabalikat Ng Pamilyang Pilipino, 3rd Floor B & M Bldg, 116 Aguirre St, Legaspi Village, 1229 Makati, Metro Manila, The Philippines.

Small actions, big changes

'Advocacy' means carrying out activities which achieve wider public understanding about issues, and changes in policies, laws and health or education services. It may involve political demonstrations but more often is a gradual process of informing and persuading key people that policy change or providing more resources is the best way forward. Advocacy involves voicing the interests and concerns of affected groups. This means including them in planning and listening to their needs.

Small organisations may fear that advocating policy change is too difficult, or that they lack skills and will be unable to change attitudes or services. It is true that national level lobbying is needed to achieve major policy changes, as happened in Cuba (see page 7). But very effective local campaigns often focus on broadening public acceptance and taking on specific issues, such as the examples on page 3.

Before starting, think about these issues:

- Why do you want to challenge the existing situation and what do you hope to achieve?
- What precise issues will you focus on, and what changes do you want? Choose a few key messages, and explain clearly how you propose to make these changes and show that they are possible.
- With whom do you want to work during the campaign? Who needs to be involved and who will strengthen your message (alliances between groups for people with HIV, health workers, human rights groups, lawyers, celebrities, religious leaders, politicians, unions, NGOs)?
- Whom do you need to influence (media, policy makers, local NGOs or the hospital, church or mosque)?
- What information will best explain your arguments and back up your demands? Make sure you have all the facts about the situation and that your arguments are persuasive and appeal to people's self-interest.
- How and when you will get your message across (letters, meetings, rallies, press releases, interviews, information updates and fact sheets)

Rau, B, Ten steps for HIV/AIDS advocacy, AIDScaptions, July 1995.

nd human rights

Practical activities

reating awareness of HIV and educing stigma The Philly Lutaaya nitiative is one example of a group f people with HIV who provide ublic education and aim to ncourage attitude change and a nore supportive environment (see age 4).

ducating health workers Women ighting AIDS in Kenya (WOFAK) is a elf-help group of women living with HIV. An HIV-positive woman asked WOFAK for support in getting a ealth worker to assist at the elivery of her baby. This had been efused because she was HIV ositive. WOFAK met local health workers and one doctor agreed to ssist at the birth. WOFAK now plans o work with other health workers o reduce their fears about infection.

Developing a workplace AIDS policy In Zimbabwe, trade unions, employers and NGOs have jointly agreed a policy which prevents employers from testing employees for HIV. In South Africa the same process has led to a parliamentary bill on HIV employment policy. The AIDS and Law Network works with employers and unions to lobby and change policy. It provides public education using pamphlets on HIV-related rights and training for community legal advisors.

Improving women's status FIDA Kenya, a women lawyers organisation, provides domestic violence awareness training to police officers. Many women dare not refuse unprotected sex with their husbands for fear of violence. The training links domestic violence and HIV infection and has changed some police officers' attitudes. They are encouraging colleagues to take domestic violence seriously and have designed posters for display in local police stations.

Ensuring housing rights In India one NGO works with local housing associations to integrate HIV awareness into their campaigns on housing, to prevent HIV-positive people from being evicted.

Supporting prisoners rights The AIDS and Law Project in South Africa provides HIV awareness training to prison officers and prisoners, and legal representation for prisoners with HIV. HIV tests are no longer done without consent and prisoners with HIV are not segregated. Prisoners say officers are much more aware of HIV-related issues.

With thanks to Renée Danziger (UK) and Dorothy Odhiambo (Kenya).

Internationally accepted human rights

These principles are from the Universal Declaration of Human Rights. The *abuses listed* are possible examples – these vary depending on national laws and policies and local circumstances.

Liberty, security and freedom of movement
- *compulsory HIV testing*
- *quarantine, isolation and segregation*

Freedom from inhumane or degrading treatment
- *isolation, for example of HIV-positive prisoners*
- *participation in research trials without informed consent*

Equal protection of the law
- *denying access to legal advice or services*

Privacy
- *lack of confidentiality or disclosure of test results without consent*
- *compulsory reporting of people with HIV to health authorities (making HIV a notifiable disease)*

Right to marry or have relationships and children
- *forced abortion or sterilisation*
- *compulsory pre-marital HIV testing*
- *discrimination against same sex relationships*

Self-determination
- *banning groups organised by people vulnerable to or affected by HIV*

Equal access to health care
- *lack of appropriate drugs or condoms*
- *refusal to care for or treat people with HIV*

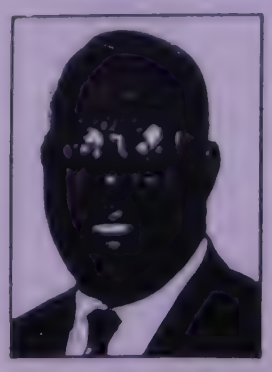
Education
- *lack of access to information which enables people to make informed choices*
- *refusal to provide education because of HIV status*

Shelter, social security and housing
- *denial of access to housing or social services*

Work and security
- *dismissal from, or discrimination at, work*
- *limited or no insurance cover or other benefits*
- *HIV testing as a precondition of employment*

Being open, educating others

In Uganda people living with HIV are organising themselves and publicly speaking out.



Major Ruranga is living with HIV and is an officer in the Ugandan Army.

'Uganda has faced up to the reality of AIDS. One reason for this is that our leaders have accepted the problem. For example, our President always stresses that we need to fight HIV/AIDS in order to fight poverty in Uganda.

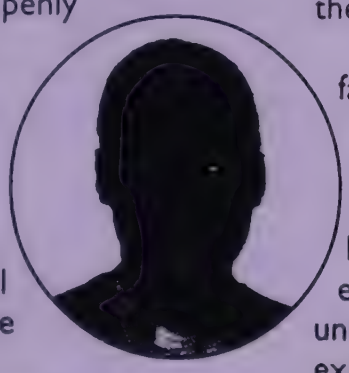
But most people in Uganda still think that HIV only affects the poor or soldiers, drivers and prostitutes. Many wealthy and educated Ugandans are not open about AIDS. These people tend to go abroad for treatment and hide the fact that they have HIV.

It is very important for powerful people who have HIV to come out openly. Keeping quiet does not reduce the pain that HIV inflicts on us. I have become involved in HIV education because I feel that people listen to and believe the voices of those who are already infected and affected more than those who are not. Better prevention can be achieved if respected and important public figures do not hide away from the issue. Everybody must join the fight because there is no need to be ashamed of a disease that does not recognise borders and can affect anyone, whatever their position in society.'

Major Rubaramira Ruranga, Guidance and Empowerment Network, c/o Joint Clinical Research Centre, PO Box 10005, Kampala, Uganda.

Reverend Gideon Byamugisha is an HIV-positive Anglican priest.

'I hope, as a priest openly living with HIV, that other priests will feel able to be frank about HIV and that if people see that a priest can get HIV they will realise that everyone is vulnerable.



Religious institutions can be great assets in the fight against AIDS. Their members have daily contact with people and are depended upon for reliable information. But without accurate information about HIV they can be a big hindrance to education, especially if they are reluctant to discuss sexuality for religious and cultural reasons.

Religious divisions over condoms are unhelpful. We should accept the 'multi-frontline' approach to HIV prevention and choose which line to fight on, without attacking those fighting on other fronts.

For three years I have been teaching church leaders about HIV prevention and care. At first they tend to say that people living with HIV should be separated and that AIDS is a curse from God. However, after an awareness raising session they change their views.

HIV is linked to community and family relationships, including marriage. Unequal relations between men and women put women at higher risk of infection. Life skills are not included in school education for young people while unequal relationships at work and exploitation and low wages make many people vulnerable.'

Reverend Gideon Byamugisha, PO Box 14297, Kampala, Uganda.

The Philly Lutaaya Initiative (PLI) is a group of men and women with HIV who educate others by sharing their personal stories.

'This project started in 1991. Our aim is to give AIDS a human face by talking to groups in the community. This encourages others to think more personally about HIV, supports those who are trying to remain free of HIV and reduces the stigma for people with HIV/AIDS.

At public sessions audiences ask many questions, such as: How have you benefited from going public? How did you get the courage to take an HIV test? Have you told your children? We try and answer as honestly and openly as possible. Each of us has a different story – some of us have children and others do not, some have chosen to abstain from sex and others have a healthy sexual life using condoms.

We discovered that young people are interested in learning different ways of saying 'No' to unprotected sex and of having safer sex rather than being told simply to abstain.

After our sessions many people decide to change their behaviour or seek further counselling and a test.'

Philly Lutaaya Initiative, PO Box 10446, Kampala, Uganda.

Below: PLI members talk to young people about living with HIV.

Philly Lutaaya Initiative

A positive response

Collaboration between people living with HIV, health workers and policy makers has changed policy in Cuba, Latin America.

From 1986 to 1990 Cuba's national AIDS policy included compulsory isolation for people with HIV in special sanatoriums, which included family visits and, shortly afterwards, weekend passes. In 1989 a group of HIV workers and people living with HIV began questioning these policies, arguing that people living with HIV need to be able to mix freely with others in order to reduce fear of HIV.

In 1990 people living with HIV and resident in Cuba's main care and prevention centre, the Sanatorium Santiago de las Vegas, formed the AIDS Prevention Group (GPSIDA). We aimed to make our voices heard, do AIDS education in the community and campaign for the right to be treated with respect.

After training ourselves as prevention educators we began working with the National AIDS Programme to ensure that their information was accurate and challenged the prejudices that people have about HIV. We targeted teacher training colleges and workplaces and used TV and radio to reach families and young people. In the 'Learning to live with HIV' project GPSIDA collaborated with staff at a test counselling centre, providing support and counselling to those who had just tested positive.

Partly as a result of GPSIDA's work, in 1993 sanatorium residents were given the choice of continuing to stay in the sanatorium or returning home and receiving outpatient or home care provided by a network of family doctors based in the community. This was a decisive step towards integration of people with HIV into Cuban society. GPSIDA educated and prepared people for the changes.

As well as changing our own country's policies, GPSIDA members and others have struggled hard to challenge assumptions elsewhere that Cubans who test positive for HIV have only one destiny – sanatoriums. We have always appreciated the benefits that the Cuban health system provides – HIV-positive Cubans get treatment and care including up-to-date medication, balanced diets and psychological support. The right to life, free health care, treatment and education are the main priorities for Cuba. When Cuba's AIDS policy is criticised our health system must be compared to those of other countries where there is less access to health care for all, including people living with HIV.

GPSIDA has always dreamt that our experience, though not perfect, can be a reality for people with HIV in other poor countries.

Dr Juan Carlos de la Concepción Raxach, founder member of GPSIDA, currently studying in Brazil.
GPSIDA, Sanatorio Santiago de las Vegas, 1 1/2 km carretera al Rincon, Santiago de las Vegas, Ciudad de la Habana, Cuba.

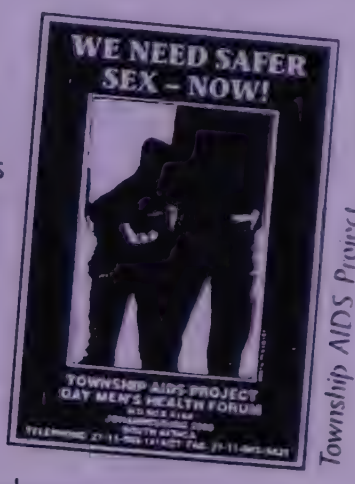
Right to know

Access to health information is a human right. This applies to HIV information, including how the virus is transmitted sexually between men. In most societies men have sex with other men. Some men are afraid to be open about who they have sex with because of fear of violent attack or discrimination. Others do not consider themselves homosexual (gay) but sometimes have sex with other men even though they normally have sex with women – for example, men in prisons or single-sex hostels.

HIV projects need to include information for men who have sex with men. Lack of information leads to a higher risk of contracting HIV. For example, some prisoners believe that they are not at risk of getting HIV because they are only having sex with men, not with women. Some men have even said to me that they opt to have sex with men because they think it is safer than women.

Disbelief and discrimination make it difficult for people to raise these issues and to design appropriate programmes. AIDS organisations are themselves often unwilling to admit that sex between men happens. The public, politicians and the media need to be educated.

Groups and organisations of gay men and lesbians are being formed across Africa. In South Africa the Township AIDS Project has a Gay and Lesbian Programme where black gay men and lesbians learn about HIV and safe sex and share experiences. Similar groups have also been set up in Botswana, Kenya and Zimbabwe.



Township AIDS Project

Recent threatening and discriminatory statements from a few political leaders in Africa and elsewhere make it difficult for gay groups and people working with men who have sex with men. As well as fighting discrimination against people living with HIV, community-based and human rights organisations need to challenge this discrimination and develop appropriate education and outreach programmes. It is important for everyone to be able to live without fear of being stigmatised because of what they do sexually, and to be able to discuss these issues.

Simon Nkoli (formerly of Township AIDS Project Gay and Lesbian Programme), Positive African Men Project, PO Box 23017, Joubert Park, 2044 Gauteng, South Africa.

On the margins: men who have sex with men and HIV/AIDS in developing countries describes the political and social contexts in which men have sex with men, and government and NGO responses. *Available free to NGOs and AIDS service organisations in developing countries from PANOS Institute, 9 White Lion Street, London N1 9PD, UK.*

Self-help or support?

'Support groups are the best medicine' says an HIV-positive woman, but their success depends on having clear aims.

Many local groups have been set up by or for people living with HIV/AIDS. They are not easy to organise and do not always meet every HIV-positive person's needs. However, they can be a great source of help and an advocacy tool, both locally and nationally.

Self-help groups can provide:

- emotional and social support at home or in group sessions
- opportunities to meet, and share ideas and practical information with others who face similar issues
- training in education, public speaking and counselling skills
- opportunities for getting loans or earning an income
- a basis for advocacy and campaigning.

It is important for the co-ordinator or founder members to be clear about the main purpose of the group and discuss this with new members. Women and men with HIV have very different needs and concerns – depending on how long they have known they are HIV positive, their state of health, their financial situation and family responsibilities.

Groups work best when their members have similar expectations. For example, recently diagnosed people may not wish to become involved in campaigning or education work. The Post Test Club of the AIDS Information Centre in Uganda offers peer counselling and practical information to people who have recently taken an HIV test. The Wednesday Club of the Thai Red Cross is run by people currently receiving treatment who want to share information.

It is easy to become discouraged if members leave but this does not always mean failure. Perhaps people join during a particular crisis, for example shortly after diagnosis. When the crisis passes they may prefer not to continue.

Some people may need material support, such as money or food, rather than the opportunity to talk. Make sure that people know if your group cannot provide this and consider whether you or another organisation can respond to these needs with a different project. One women's group in Zimbabwe saw the need for economic support, and set up a successful tailoring business with a supportive working environment. It has decided that it cannot accept new members.

Meeting as a group may not always be appropriate. A group in Côte d'Ivoire found that few women join because they are afraid for their children if their HIV status becomes known. Members visit women individually at home.

Groups are more likely to succeed if they are run by people living with HIV and where members share similar experiences, for example as women or as injecting drug users.

Support and self-help groups can play an important role in advocacy. By enabling people living with HIV to get together it is easier to be open and become involved in prevention and care. This shows others that people with HIV are living positively, sharing the burden of policy and education work.

Thanks to Emily Chigidwe (Zimbabwe), Joanne Manchester (UK), Nina Okagbwe (Côte d'Ivoire) and Dorothy Odhiambo (Kenya).

Anger into action

'One of the hardest parts of living with HIV or AIDS is dealing with the anger and frustration of a disease that makes most of us feel powerless. Last year a group of women went to a talk by a medical professional who used words that most of us did not use or understand. At first we felt angry, but then we decided to do something about it.

We decided to set up a school run by ourselves – called the HIV University – for women to learn together about HIV, support one another and learn to advocate for better health care. First we planned a curriculum. There was so much we wanted to learn, but we decided to focus our16 classes on: how the body works; what is HIV and HIV disease and how we can protect ourselves; reproductive health and STDs; safer sex; nutrition; treatments and side effects; alternative/complementary therapies; clinical trials; how to talk to your doctor; addiction; spiritual and mental support; and sharing what we have learned with others.

Once we had decided on these topics we contacted people in the community to help us. Some were living with HIV. Others were from service agencies, which was helpful in improving communications and access. All volunteered their time. We drew up guidelines for resource people, which included explaining complicated words, using objects and pictures such as samples of medicines or pictures of body parts, allowing time for questions and making lessons relevant to our lives.

All students signed a contract agreeing to respect confidentiality, respect others' beliefs and stay at home if they have an infectious illness in order not to infect others. The curriculum changes with each new group of women, depending on personal priorities. Each class is different and some women join twice. Because the women choose the curriculum we know we are meeting their needs. We have witnessed miracles in each other's lives – changes and growth. We have chosen to claim responsibility for our own lives.'

Sandi Luna, WORLD, 3948 Webster Street, Oakland CA 94611, USA

Making a living

Many income generating schemes end in disappointment. ***AIDS Action*** *highlights issues to consider before starting.*

The most serious problems faced by people living with or affected by HIV are poverty and inequality. Income generating activities aim to solve these problems but often fail. Many create extra work for members with little economic reward. Others may improve incomes in the short term but fail because they depend on continuing outside support.

The real barriers to improving income may not be economic at all, but social or cultural. For example, increasing women's income may simply result in their partners taking the money. It is important to think about possible problems and barriers before beginning an income-generating project, and to consider other options for addressing poverty.

Responding to needs

Is the activity intended to be a viable business enterprise or to provide social support to people? Income-generating projects can provide personal, as well as material, benefits, but this aim needs to be clear from the start so that people do not have unrealistic expectations.

Is the main aim to provide financial security to people who are in need? If so, find out what sources of support already exist locally, for example:

- referring people to church or welfare groups
- providing assistance to obtain government benefits
- creating welfare funds for small one-off payments
- establishing vegetable gardens or helping people to produce household articles for family use.

Before planning a new activity think about improving existing employment options, which might include:

- identifying local employment needs and planning appropriate training
- arranging temporary work with local employers
- training people who already run small businesses in production or business management.

Saving and borrowing

A common problem for people trying to start a business is lack of access to credit (loaning money on a commercial basis to be paid back, usually with interest).

Are there any local credit or savings schemes such as Islamic credit schemes, women's savings groups or revolving loan funds? These schemes involve members making regular small contributions to a fund which entitles them to an occasional loan or payment.

Consider all the real costs of setting up a credit scheme, including salaries and office rent. A service charge may be needed to cover the running costs, especially in rural areas where communications are costly.

Plan the scheme carefully, making sure that people understand the need for repaying money with interest. Give adequate support to beneficiaries, such as ensuring women members have access to literacy and basic financial skills and child care.

Enterprise

If you think there is a business opening, first ask yourself why no-one is doing it already. Business enterprises fail for many reasons, including lack of training, skills or access to markets. Test your ideas with local, sympathetic entrepreneurs or business development projects.

If you do plan to set up an income generation project think about who will be involved. The best projects are often those set up by the potential participants themselves.

Should the project work with individuals or groups? Working in a group is not always easy. Different members may have different aims. However, costs can be reduced if a group pays for materials or transport. Make sure that individuals benefit directly from group membership.

Be clear about your organisation's capacity to cope with the increased work load and ability to carry out a commercial enterprise.

Financial sustainability is not always possible, especially where there is high inflation, sickness or conflict. In these situations, external donor support may always be needed. It is important to remember the other benefits of income generating activities as well as, or instead of, improving financial security. If a project is well-targeted and efficient, clients gain not only income (their dependents also benefit indirectly) but also new skills which may contribute towards increasing control over their lives.

Thanks to Judy el-Bushra, ACORD, UK.

AIDS support and income generation, 1994, Global AIDS News 4, Jackson, H, Mouli, V C & Udwin, M.

P Almasy/WHO

Credit schemes can improve financial security for small businesses.

LETTER

Fighting injustice

I am 41 years old and several years ago chose to volunteer as a home carer with my local church. I already knew about the experiences of people living with HIV, having seen two of my relatives go through physical suffering and mental pain caused by others avoiding people with AIDS. I received training in pastoral counselling and pre- and post-test counselling. Shortly after volunteering I decided to take an HIV test myself. My husband's first wife was quite sick and I wanted to know for myself. I was influenced by the example of the many people with HIV dying with dignity.

When I received the news that I was positive I was emotionally out of it for some time. I didn't know what I was hearing. I was worried about my daughter. I asked the counsellor to pray with me and then returned to my HIV training class.

I have chosen to tell other people because I want to be honest with them. I first shared my news with the nursing sister, my pastor, and then with the eighteen other counsellors. I did so because I wanted to talk to people about the dangers of AIDS and having many sexual partners.

I feel very strongly about some of our customs which make life more difficult for women, such as wife inheritance and the fact that a husband's family inherits the widow's possessions even after a legal marriage. Women need to know there are laws which govern a divorce. The practice of bride price means that, if her family needs the money, a woman cannot avoid getting married to someone she knows is sick. When men have more than one wife they just chase a sick wife away.

There are also cultural practices which do not help women. They need to have access to good food which is difficult. For example, a pregnant woman is not allowed to eat eggs. Another problem is that many people spend large amounts of money to counteract bewitching, which they believe is the cause of sickness.

I will continue to help women write their last testaments and help them provide for their children. I believe that each of us can live positively with AIDS and that we don't have to give in to unjust practices.

Anna Kitwala, with Sister Veronica Schweyn, Mwanza, Tanzania.

RESOURCES

AIDS, health and human rights: an exploratory manual links public health and human rights issues with HIV. *Available for Swiss francs 20.00 from International Federation of Red Cross and Red Crescent Societies, PO Box 372, CH 1211 Geneva 19, Switzerland.*

Challenges of going public: commonly asked questions and answers to people going public and **Stepping out in the open.** *Available from PLI, PO Box 10446, Kampala, Uganda (contact PLI for price information).*

Empowerment through enterprise provides guidelines for NGOs to support self-employed people. *Available for £11.95 from Intermediate Technology Publications, 103-105 Southampton Row, London WC1B 4HH, UK.*

Income generation schemes for the urban poor provides basic guidelines for NGOs starting income generation projects. *Available for £8.95 from Oxfam Publications, 274 Banbury Road, Oxford OX2 7DZ, UK.*

People living with HIV: the law, ethics and discrimination and **Women, the HIV epidemic and human rights: a tragic imperative** outline advocacy and strategies on human rights. *Available free from HIV and Development Programme, UNDP, 1 United Nations Plaza, New York NY 10017, USA.*

For more information about groups for people living with HIV and AIDS contact Global Network of People Living with HIV and AIDS (GNP+), PO Box 11726, 1001 GS, Amsterdam, The Netherlands and International Community of Women living with HIV & AIDS, PO Box 2338, London W8 4ZG, UK.

New resources

Africa against AIDS is a catalogue of African AIDS education materials in English, French and Portuguese. *Available free for developing countries (£10 elsewhere) from AHRTAG.*

Broadening the front describes NGO responses to HIV and AIDS in India. *Available for £2.75 from TALC, PO Box 49, St Albans, Herts AL1 5TX, UK.*

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Blood safety

Ron Gilling/Panos Pictures

Responsible giving and effective screening procedures mean that donating blood can save lives.

HIV-infected blood transfusions are responsible for between 5 and 10 per cent of HIV transmission in developing countries. Ensuring sufficient supplies of safe blood poses ethical and financial challenges in under-resourced countries where many people are at risk of HIV, or already living with the virus. Collecting infected blood wastes time and money and risks the lives of recipient patients.

The HIV epidemic has a major impact on blood collection strategies. Ideal blood donors are healthy adults and young people, but these individuals are likely to be sexually active and at risk of HIV. More people are reluctant to become donors because they don't want to consider their personal risk of HIV, or fear that their confidentiality will be broken. Others use the blood collection service as a way to find out their HIV status.

Individuals who do test positive for HIV need to be sensitively referred for counselling and follow-up. This must be done in a way which does not breach people's privacy or lead them to be questioned by their friends or colleagues about why they are not donating blood.

Increasingly, blood services are linking education about giving safe blood with having safer sex. They are working more closely with organisations and health services involved in HIV prevention and care. Collaboration helps to make safe blood collection easier and more successful. Staff can provide public education about what happens during the blood collection process, and the serious responsibility of giving safe blood. Many may also have a key role in counselling people who have been referred by the blood transfusion service.

Success stories

The most successful strategy for a safe blood supply involves encouraging people who are at low risk of HIV infection to give blood, and counselling them about the need to be responsible donors, deciding not to give blood if they have been at risk of HIV.

It seems that this strategy may be having a double benefit. Less HIV-infected blood is being collected, thus reducing the risk to recipients. And, significantly, regular blood donors are showing that they have a key role in educating others about giving blood and HIV prevention, and that they themselves are keeping up safer sexual behaviour. Research from Uganda and Zimbabwe shows that both young people and adults who give blood regularly are more likely to remain HIV-negative than non-donors.

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Strategies for safe blood

Receiving an HIV-infected blood transfusion carries more than a 95 per cent risk of HIV transmission. AIDS Action explains how blood can be made safe.

Trygue Bolstad/Panos Pictures

All donated blood needs to be screened for HIV, hepatitis B and syphilis.

Donating safe blood

The best way to ensure that donated blood is free from infection is to encourage donation by people who are:

- unpaid and willing to donate blood voluntarily, responsibly and regularly
- at low risk of HIV and other infections transmitted by blood
- healthy and fully grown in order not to affect their own health, and not pregnant or anaemic, or suffering from any infections
- informed about the tests to be done on their donated blood, including HIV.

Schools, universities, church groups, community centres and workplaces provide opportunities for educating and recruiting people at low risk of HIV. Public education and sensitive counselling can help people to decide not to give blood if they feel they have been at risk (self-exclusion).

Key points

Blood transfusion services use three main strategies to reduce the risk of transfusing infected blood:

- minimising the number of HIV-infected blood donations by recruiting and counselling voluntary unpaid donors who are at low risk of HIV
- testing (screening) all donated blood for HIV and other infections transmitted by blood and safely disposing of infected blood
- reducing the number of blood and blood product transfusions.

Blood transfusion services are developing these strategies by: setting up a donor selection process; training staff in education and counselling skills; providing a regular supply of equipment for collecting, screening and storing blood; using blood transfusion guidelines; and ensuring quality control.

Avoiding unsafe donations

Using donors who are paid to give blood is likely to lead to a commercial, often illegal, blood trade and an unsafe blood supply. The people who have to sell their blood in order to make a living are often those at most risk of serious communicable disease.

Blood donation should never be compulsory, and should not be carried out in institutions such as prisons or the army. Even if the authorities encourage voluntary donation, it is often hard for people to decide freely whether to give blood. Positive results often lead to discrimination, such as isolation in prisons or dismissal from army service.

In rural areas where blood supplies are scarce, members of the patient's family are sometimes asked to donate their blood. However, this should be avoided unless there is no alternative. In some areas where HIV is common up to half the blood donated by family members is HIV infected and has to be destroyed.

Health workers faced with this situation should take the family member's blood for testing but use an existing tested unit from the hospital blood bank for the patient. The donor should be told that their blood will not be used for their own relative but, if proved free from infections, will instead be deposited in the hospital blood bank.

Family donors should always be counselled before donating and their blood only collected if they meet the national criteria for blood donation (see pages 4 and 5). If they do not have HIV they should be encouraged to become regular donors.

Screening blood

All donated blood needs to be tested for the presence of infections that are transmitted by blood: HIV, hepatitis B and syphilis. Tests for hepatitis C, Chagas' disease and malaria may be carried out, depending on local disease prevalence and national policy. Blood giving unclear or positive test results for any of these conditions should not be used and be safely disposed of, by incineration, for example.

Occasionally a person whose blood tests HIV negative does in fact have HIV. This is usually because of the

window period'. HIV tests do not detect HIV itself but antibodies produced by the immune system in response to infection with the virus. However, it can take up to three months for these antibodies to be produced.

During the window period an HIV antibody test will produce a negative result even though HIV is present in the blood and may be transmitted. It is therefore very important for anyone who has had possibly risky activity during the past three months to be advised not to give blood.

HIV test kits used by blood collection services must be of high quality and the instructions followed exactly. The test used depends on local hospital or national recommendations but it needs to identify all possible HIV infections. This means that the test must be highly sensitive, meaning that it has a low number of false negatives (blood testing negative which is in fact positive).

If a blood bank is testing at least 40 blood samples each day an ELISA test will be the most cost effective. If less than 40 blood samples are tested a reliable simple/rapid HIV assay will be more cost effective than an ELISA test.

However, highly sensitive tests can produce false positive results (blood testing positive which is in fact negative). Therefore a positive result does not necessarily mean that the person is infected with HIV.

People should not be informed of their results after only one positive test result. A second blood sample must be tested. Ideally the test needs to be a different test. It does not need to be a Western blot test but should be done independently of the first test and accurately checked.

People should be informed of their HIV infection only if the results of both tests are positive, and if counselling and follow-up support are available.

Reducing blood transfusions

Despite rigorous HIV screening procedures, a few infected blood units may go undetected. It is important to reduce the number of transfusions to the minimum, to keep the risk of infecting patients as low as possible and to save costs and blood product use.

Blood transfusion guidelines can help prevent over-use of blood products. For example, in rural Tanzania, staff at district, mission and referral hospitals were trained to use guidelines including:

- precise indications for prescribing transfusions to children, pregnant women and other adults with severe anaemia; to patients with acute blood loss; and during, before and after operations
- using blood substitutes where possible such as saline, for example to replace the amount of fluid in circulation after a haemorrhage
- using the patient's pre-collected own blood when surgery is planned
- not using a single unit transfusion of blood as a 'tonic' (often used for 'topping up' blood when someone is weak from anaemia or after an operation).

H.Anenden/WHO

The risk of transfusing HIV-infected blood must be kept to a minimum.

The project also recommends the following strategies:

- setting up a blood transfusion committee to monitor blood use
- regular continuing education and supervision on using guidelines
- clinic meetings where blood transfusions can be discussed by staff
- ensuring that staff provide clear reasons when prescribing blood transfusions on a request form.

Most importantly, illnesses and conditions requiring blood transfusions need to be better prevented. In developing countries most blood transfusions are given to children and women for anaemia or pregnancy complications. Community health care programmes need to provide treatment for malaria and worms for pregnant women and vulnerable children, and to improve nutrition, water supply and sanitation.

With thanks to Dr Jean Emmanuel, Chief, Blood Safety Unit, WHO; Dr Robert Beal, Interim Director, Blood Dept, IFRCRC; Mr David Mvere, Technical Director, RK Shamu, National BloodTransfusion Service, Zimbabwe; Dr Zarina Bharucha, Head, Dept Transfusion Medicine, Tata Memorial Hospital, Bombay, India.

Source for Reducing blood transfusions:
TANESA Project,
PO Box 434, Mwanza, Tanzania.

What is hepatitis B?

All blood should be screened for hepatitis B, a viral illness which can affect the liver. The infection can be symptomless, but tiredness, yellowing of skin and eyes and loss of appetite are common. Most people recover completely from the early acute infection without treatment, but 10 per cent develop chronic hepatitis, remain infectious to others and may develop liver disease which can lead to death.

The virus can be spread by saliva as well as other body fluids. Common transmission routes are: from an infected mother to her baby before or during birth; during unprotected sex with an infected partner; through an infected blood transfusion; through intimate contact with an infected person, such as through sharing toothbrushes or razors; and by contaminated injecting equipment.

A blood test is the only way to know if someone is infected with hepatitis B. People carrying the virus need education about caring for themselves, such as limiting their intake of alcohol, and preventing transmission by not sharing toothbrushes or razors, and having safer sex. In some countries children are now routinely vaccinated against hepatitis B, as well as close family members of people with chronic hepatitis.

Blood may also screened for hepatitis C, a more recently discovered form of the virus which is transmitted mainly by blood and causes chronic disease in most people infected.

Safe blood and

Fears about giving blood

'I'm worried that my test results for HIV or syphilis will be made public.'

Good systems of confidentiality need to be developed and clearly explained to donors.

'I'm scared of being infected with HIV while giving blood.'

There is no risk of infection because a new needle and syringe are used for each person.

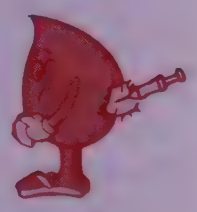
'I'm worried that giving blood causes physical weakness or infertility.'

Many donors have given blood over 50 times, up to four times a year, without any harm to their health.

'I can't give blood because I think I'm anaemic.'

Before taking blood, a simple test is performed on a drop of blood taken from a finger prick to find out if the person is anaemic.

'I hate needles.'



A local anaesthetic is applied to the skin to make sure that giving blood is not painful, and the donor does not have to watch the procedure.

'It's too inconvenient and I'm too busy'

Giving blood can mean life itself for a patient, and even the busiest people find time to donate.

Adapted from Fiji Red Cross leaflet.

Education and counselling for donors not only contribute to making the blood supply safe, but also to promoting safer sexual behaviour.

Public education

Basic information is provided in leaflets, newspaper articles and television or radio advertisements. Donors can be recruited during campaigns or talks at church groups or schools. Messages should emphasise the positive reasons for giving blood, including stories about lives saved with blood transfusions. Education should also highlight the serious need for people to be responsible donors who do not put patients at risk of HIV or other infections.

Before donating blood

When people come to the blood collection centre or mobile van, it is helpful to give a talk or show a video to small groups about the counselling and blood collection process.

The key messages are:

- what happens when you decide to give blood
- why regular safe donations are needed
- your donated blood is tested for HIV and other infections
- basic facts about HIV and HIV prevention
- your confidentiality is guaranteed
- the importance of deciding not to donate blood if you think you may have HIV or another infection (self-exclusion)
- where to go for counselling and HIV testing, if you wish.

One-to-one counselling

Ideally each potential donor should have a one-to-one talk with a trained health worker before blood is collected. Staff need to be able to provide accurate information, ask and answer questions sensitively, and refer people to other sources of support.

People wanting to give blood may not have seriously considered that they may have HIV infection. However, it is also very important that people are discouraged from using blood services as testing centres. The counsellor or nurse should check that the person understands how HIV can be transmitted and explain which tests will be done and why, and what the window period is (see page 3). He or she should also explain that blood may not be used for a number of health reasons, including anaemia or syphilis, which can be cured.

Donors need to know why personal questions, for example about their sexual activity and injecting drug use, are necessary. Discussing these issues helps people to decide whether they should donate blood or if they should exclude themselves because they may have been at risk of HIV.

The Namibian transfusion service found that potential donors had difficulty filling in a 'self-exclusion' questionnaire on their own. Now a trained nurse goes through it with each person and answers any questions. The questionnaire lists activities which exclude the person from donating blood, such as ear and skin piercing, tattoos or traditional skin incisions, any past sexually transmitted infection or common HIV-related symptoms such as night sweat, swollen glands or persistent diarrhoea.

In Honduras the Red Cross National Blood Programme provides pre-test counselling for voluntary blood donors. Leaflets contain information about HIV and the importance of not donating if the person has engaged in activities associated with high risk of infection.

Each potential donor is asked to read the brochure. A nurse encourages questions and checks that the information has been understood. The nurse then asks specific questions about sexual behaviour such as all forms of unprotected sex including sex with other men and any history of sexually transmitted diseases. When

safer sex

Information for blood donors

- Your name will not be used at the blood bank. Instead we use your mother's unmarried name, your birthplace and your date of birth.
- You will be given a code number which is used on all your records and blood samples.
- You will be asked some questions about your health to make sure that giving blood will not harm you.
- You will be asked questions about your private life to ensure that our test results are accurate.
- A sample of your blood will be taken by finger pricking and tested to make sure you have enough blood to spare for a donation.
- If so, we will draw your blood. Afterwards we will ask you to rest for a few minutes, take some refreshment to replace the fluids you have lost and take some iron pills to help your body replace the donated blood quickly.
- The blood you have donated will be tested for hepatitis and HIV viruses.
- The results of these tests will be available to you (and no-one else) in two weeks if you choose to know them.

Please do not give blood if:

- in the last six months you have had sex with someone other than your regular partner; or
- in the last year you have had:
  i) an injection except at a hospital or clinic
  ii) skin scarring or cutting by a traditional healer
  iii) a surgical operation; or
- you have ever had hepatitis (jaundice causing yellow coloured eyes)
- you are pregnant, have had malaria or a sexually transmitted infection.

Please do:

- if you have given blood before and it has been found safe
- when three months have passed since your last donation.

Adapted from Uganda Blood Transfusion Service information leaflet

this counselling session was introduced in 1991, HIV prevalence among blood donors dropped from 0.38 per cent in 1990 to 0.19 per cent a year later, even though overall numbers of Hondurans with HIV continued to increase.

If they do give blood, donors also need to decide whether they wish to know their HIV test results. However, as explained on page 3, this option should only be given if a second test is possible, and counselling and support services are available.

After donating blood

It is very difficult for many blood transfusion services to provide post-donation counselling for people with positive test results. If HIV counselling and care or treatment services are not available, people should not be informed of their results. However, referral links can be set up with existing counselling organisations (see page 6).

Negative donors are sent newsletters and invited to donate again, or to join a blood donor association. This provides an excellent opportunity to reinforce education they received before donating blood. It encourages them to become regular donors, as well as talk to others about safer sex and safe blood.

With thanks to Dr E Vinelli, Medical Director, National Blood Programme, Cruz Roja Hondureña; Mr D Mvere, Technical Director, National Blood Transfusion Service, Zimbabwe; Dr S Kalibala, UNAIDS; Dr Y Sliep; Dr Chaivej Nuchprayoon, Director, National Blood Centre, Thai Red Cross Society.

European Commission 1995, Safe blood in developing countries: the lessons from Uganda.

Keeping up commitment

Zimbabwe's National Blood Transfusion Service found that school students, aged 16 years and over, have low levels of HIV infection.

Basic education is provided through school talks, where students are invited to give blood at mobile blood collection vans. Each year, a shield is awarded to the school in each region providing the most donors. Students are also recruited from some schools to be peer promoters, trained in blood donation education, and involved in designing educational materials and approaches. In these schools, recruitment has doubled and students are also more likely to continue giving blood.

School students now contribute about 65 per cent of the country's blood supply. However, staff are aware that new HIV infections may be common even in groups with lower prevalence levels of HIV. For example, in some areas the number of school-age girls with HIV is increasing very rapidly.

Staying safer

Analysis of blood donor information shows that adult donors who return to give blood and receive counselling are less likely to have blood-borne infections than first time donors. People who have already donated safe blood need to be encouraged to donate regularly, and to remain HIV negative.

Zimbabwe's blood service targets school leavers, by inviting them to register for attendance at regular blood collection sessions in local community centres. School leaver donors have tripled since the programme started in 1993, and analysis shows that they continue to have low levels of HIV.

Some students set up the 'Pledge 25' Club in 1994 where school leavers promise to donate blood 25 times in their lives and try to remain HIV negative in order to be able to do that. Members of the Pledge 25 Club and peer promoters celebrate a national Youth Donors Day in December each year, where many new blood donors are recruited.

In Zimbabwe, badges, caps, scarves and plaques are awarded to regular adult donors. Special occasions are held where people who have donated for long periods are honoured. Press coverage of these events often motivates other people to give blood. Regular donors also have a key role to play as educators and role models in their communities.

Testing positive

Providing counselling for donors who test HIV positive poses key challenges for blood services and counselling groups.

Ideally, people who may be HIV positive should be encouraged not to give blood. However, if the person decides to give blood, they should be given the option of knowing their results.

They should only be informed if two test results are positive and follow-up counselling and support are available. After talking with a counsellor, people may decide not to give blood but may also want to be referred for an HIV test. Many blood services are trying to link up with NGOs and hospital counselling services.

In 1993, Zimbabwe's blood service reviewed its notification systems after some donors expressed anxieties about confidentiality, especially in relation to HIV, and numbers of adult donors were declining. In the past, people were referred to their doctors, but many donors either did not have a doctor or were reluctant to discuss HIV or syphilis infection with them.

Now, donors with positive test results for HIV, syphilis or hepatitis are informed by mail that they have an unspecified infection, but are offered counselling and follow-up at an organisation or doctor of their choice (who are also sent letters explaining the situation).

However, NGOs which provide counselling have difficulties in following up donors. In Zimbabwe some NGOs reported that less than half of the people referred to them came for counselling. Common reasons included: people's unwillingness to go to the local 'AIDS centre'; fears about which infection they had, or that they had HIV; worries about being referred to a counsellor whom they already knew personally; difficulties in travelling to the counselling centre during its opening hours; and problems with the postal service.

HIV counselling services often receive referrals for other blood infections, such as syphilis or hepatitis, but counsellors may not have enough information on these illnesses.

Young donors

In many countries school age donors are recruited because they are at low risk. It may be best only to recruit students who are legally adults, who therefore can consent to being tested and to receiving their test results without their parents' permission.

Some blood services invite parents to approve the participation of their children, although there is still debate about whether to involve parents in counselling if the young person tests HIV positive. It may be more difficult to confidentially inform and support young people who test HIV positive, especially if they are at school, and if other students are becoming regular donors.

Counselling services and blood transfusion centres need to have a policy on recruiting young donors, and counselling them if they are diagnosed HIV positive.

Other HIV testing options

Individuals who are worried that they have HIV often use blood collection services in order to find out their HIV status, rather than to donate blood. This increases the risk of an unsafe blood supply. Independent counselling and testing services help the blood supply to become safer, by making sure that people who want an HIV test can obtain one.

With thanks to Dr S Kalibala, UNAIDS and Mr David Mvere, NBTS, Zimbabwe.

Counselling organisations can help the blood transfusion service by

- encouraging head teachers or employers to allow enough time for pre-donation education and counselling, and post-donation counselling and support
- educating the blood service staff, head teachers and employers about HIV to make sure that confidentiality is respected and discrimination does not occur

Blood services can help counsellors by:

- organising adequate pre-donation counselling before taking blood, to help people decide not to give blood if they have engaged in risky activities, or to encourage them to return for counselling if they are notified of possible positive results
- ensuring that, if the first HIV test is positive, a second test is carried out and is positive, before informing someone that they have HIV
- making sure that referral information is passed to the counselling service before it is mailed to the donor so that the counsellor has full information and time to prepare
- making sure that the donor information contains information about the advantages of knowing results.

Effective counselling

- Wherever possible, the same person should do the pre-donation and post-donation counselling, before referring.
- Pre-donation counselling should include talking about what it means for a person to know their HIV status.
- Blood donors should know that they will be referred if their blood cannot be used, because of other infections, malaria or anaemia and not only HIV.
- Counsellors need information about infections such as hepatitis and syphilis, in local languages, and to know where to refer people for treatment.
- Donors need to understand the meaning of an unclear or false positive result.

Towards better counselling

Keeping confidences

This training exercise aims to help counsellors think about the importance of trust and what might happen if someone's test results are made public.

People's greatest concern about giving blood is that their confidentiality will be broken. Confidentiality is essential both to protect people's privacy and help them to feel safe about discussing their personal experiences.

1 Introduce the exercise by raising the issue of confidentiality. Remind the group that people feel more able to discuss personal issues and feelings if they trust that the counsellor will not tell anyone else without their permission.

2 Split the group into pairs. Ask each person to think of someone they trust and write down ten words describing them, such as friendly, close, and honest.

3 Ask each pair to read out their words to the larger group and write them on a large sheet of paper, noting common words.

4 Split the group into smaller groups of three or four people to discuss the following questions:
What do you need to say and do when you are counselling someone to help them have confidence in you? What do you need to do to enable them to keep trusting you? What might happen when confidentiality is broken? What are the benefits of maintaining confidentiality? Invite one person from each small group to report back to everyone.

5 Then give each small group a situation (two examples below), and ask them to discuss their reactions and feelings about being in that position.

You have been diagnosed with HIV. During counselling the counsellor promised that he was not going to tell anyone about your diagnosis without your consent. Three days later you receive a phone call from a friend who wanted to confirm the news that you had HIV. Your friend has heard this from your counsellor.

You work in a factory and the blood collection team arrives. While you are doing the questionnaire you mention to the nurse that you were treated for a sexually transmitted infection four months ago. Your blood is not collected. Later a friend mentions to you that the person next in the blood donation queue saw your form and is telling all your work colleagues that you have AIDS.
Is this situation likely to happen? Why might it happen? How would it make you feel? What would you do or say in that situation? As counsellors, how would you prevent it from happening?

Source: Mr T R Makoni, National Blood Donor Counselling Co-ordinator, NBTS Zimbabwe.

Assessing personal risk

This activity helps counsellors to think about how they handle risk in their own lives, and increase their understanding of why other people take risks and their feelings about this. Before deciding to take an HIV test people need time to think about what it may mean to discover they have HIV. Many people feel anxious about discussing their personal risk of HIV (often for the first time) and are worried about being judged.

1 Invite participants to consider the following on their own for a few minutes:
'Think back on your own life and identify any occasion when you took a risk – related to sex and relationships, to work or to money, for example. It may have been a small risk or a big one that was very important to you at the time.'
– What factors influenced your decision to take a risk?
– What were your feelings at the time?
– What was the result of taking that risk?
– Do you generally take risks?
– How do you view risk taking in others? How does risk taking among your friends affect you?
– How does this affect your attitude towards the risk of HIV?

It may be useful to write these questions down.

2 After a few minutes ask everyone to choose a partner and share as much of their situation as they wish. Each person should talk for a few minutes and then listen to the partner's story.

3 Invite everyone to join the full circle. Encourage them to explore links between how people deal with risk and ways in which it may affect their responses to HIV/AIDS.

It may be useful to make the following points:
– We often feel that it is all right to take risks if they turn out well. But we tend to blame others if they take risks and things go wrong.
– We are generally much less harsh in judging ourselves than we are in judging others. Is this fair?
– We are all taking risks all the time.

4 Then invite people to link this discussion with their counselling work. How can they introduce the subject of risky sexual behaviour without being judgemental? How can this be linked to information about safer sex and reducing the risk of HIV infection?

Source: Working with uncertainty, published by FPA England.

One world?

'One world, one hope', this year's theme for World AIDS Day, December 1, was also the key message for participants at the IX International Conference on HIV and AIDS, held in Vancouver, Canada in July.

Presentations revealed the extent to which we are living in a divided world, highlighting the great gulf between people living with HIV in high income countries and those in poorer countries. Over 90 per cent of people living with HIV are in developing countries, which receive only 8 per cent of global spending on AIDS. Sessions also showed how HIV follows discrimination and inequality within countries – everywhere people in poverty are most affected, and have least access to care.

However, participants from Africa, Asia and Latin America felt that some of their key priorities were being discussed. Some successes should give encouragement to *AIDS Action* readers. Researchers in countries such as Uganda and Thailand, where there are vigorous community-based and government prevention campaigns, announced that the rate of HIV transmission is slowing down. Behaviour change and prevention messages are slowly getting through, and there is greater commitment to policy change and building more supportive economic and social environments.

Scientists have found out more about how the virus works, which has led to major developments in anti-viral drug therapy. There is now proof that taking a combination of different types of anti-viral drugs keeps people healthy for longer and reduces viral reproduction. However, these drugs are still in development, and are beyond the reach of most people – costing US$15,000 per person annually. It is still unclear whether HIV will become resistant to combination therapies over time, especially if not taken regularly. There are also some interactions with other drugs used to treat HIV-related infections which need careful management.

The research has raised many questions as well as some answers, and there is still no cure for AIDS. The main emphasis still needs to be on challenging inequalities within and between countries, and making sure that everyone has access to essential medicines and care, as well as preventive education and social support.

RESOURCES

Counselling for HIV/AIDS: a key to caring covers counselling service management and policy issues for planners and managers.

Source book for HIV/AIDS counselling training provides guidelines for developing training courses and participatory activities. *Single copies of both books in English available free from UNAIDS Information Centre, c/o WHO, 1211 Geneva 27, Switzerland.*

Guidelines for blood donor counselling on human immunodeficiency virus (HIV) explains how to integrate donor selection, risk assessment and HIV counselling into blood donor programmes, for programme planners and staff. *Single copies in English, French and Spanish available free from International Federation of Red Cross and Red Crescent Societies, PO Box 372, CH 1211 Geneva 19, Switzerland or WHO (see below).*

Safe blood and blood products is a distance learning course (five manuals) containing guidelines for managing safe blood transfusion and donation (WHO/GPA/CNP/93. *Available in English (order no 1930050) for Sw.fr.84/US$60 (developing countries) or Sw.fr.120/US$84 from WHO/DST, 1211 Geneva 27, Switzerland.*

New resources

TB/HIV: a clinical manual is a clinical management guide for clinicians in resource-poor countries. *Available for Sw.fr. 12/US$10.80 in developing countries from WHO (as above).*

Starting the discussion: strategies for making sex safer is based on the popular series Let's Teach about AIDS, and provides guidelines for participatory education on HIV, gender and relationships. *Available free to readers in developing countries and for £5/US$10 to readers elsewhere from AHRTAG.*

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Tackling HIV and TB

AKAP

Community education programmes are needed to reduce discrimination — for both TB and HIV infection.

A third of the world's population is infected with tuberculosis (TB). Every year three million people die from TB, mostly in developing countries where it kills one in five adults. Despite the development of effective anti-tuberculosis drugs, TB causes more deaths than any other infectious disease. It is now one of the main causes of death in people with HIV infection and, since the mid-1980s, has increased dramatically in developing and industrialised countries. Like HIV, having TB is associated with poverty and often results in discrimination and stigma, and abuse of human rights

But TB can be cured. With correct treatment, people with TB — including those who also have HIV infection — are no longer infectious after two to three weeks and almost all are cured after taking appropriate drugs for at least six months Without treatment more than half of those with TB are likely to die. Proper treatment also prevents the spread of TB because it makes people non-infectious

What is TB?

Tuberculosis is usually caused by infection with the bacillus *Mycobacterium tuberculosis*. TB normally affects the lungs — this is called pulmonary TB Sometimes the TB germs enter the bloodstream and spread to other organs in the body — this is called extra pulmonary TB Pulmonary TB is much more common than extra pulmonary TB

When a person is exposed to TB germs and becomes infected, they have TB infection (or latent TB Sometimes the infection progresses to TB disease (tuberculosis, active tuberculosis or active disease)

Once infected with TB a person remains infected for the rest of their life. But most people do not become ill with TB disease and infectious to others. A healthy immune system can stop the germs from multiplying enough to cause illness But the TB germs may continue to multiply and destroy the lung tissues, leading to active TB disease, particularly if a person is in poor health, or has HIV infection

The symptoms of pulmonary TB disease are cough for more than three weeks (sometimes with bloody sputum) and chest pain. Exhaustion night sweats, fever and weight loss are symptoms of both pulmonary and extra pulmonary TB

Active pulmonary TB is the only form of the disease which is infectious, spreading from person to person via the air. The lungs of a person with active disease develop cavities (spaces) which are full of TB germs. When the person coughs or sneezes, large numbers of TB germs from the lungs are sprayed into the air in tiny droplets. Family, friends and health workers who have close contact with a person who has infectious TB are at greatest risk. TB spreads most easily in over-crowded and badly ventilated places

SPECIAL ISSUE
HIV and TB

TB prevention and treatment

HIV and TB links

Education and training

Current issues:
- drug resistance
- preventive TB therapy

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Continued from page 1

Sputum smear tests are used to find out if a person has active TB and is infectious. A positive sputum smear test means that a person is coughing up TB germs and should be treated.

A growing crisis

WHO has predicted a global TB epidemic, causing 30 million deaths during the 1990s. The number of new TB cases worldwide each year is expected to increase from around seven million in 1990 to over ten million by 2000. There are two main reasons why TB is a growing problem: neglect of TB programmes and the spread of HIV.

Effective TB control requires a properly functioning health service with good management, diagnostic facilities, trained staff and regular drug supplies including reserve stocks. But financing TB programmes has not been a priority.

There has also been little community education to tell people about TB symptoms, reduce discrimination and to encourage them to seek treatment.

In some places there has always been a stigma attached to TB. People risk losing their jobs and housing if it becomes known that they have TB. The stigma and stress may be worse for women. In some cultures, having TB may make it difficult to find a husband or result in divorce. Links between HIV and TB are worsening the stigma.

Worldwide the number of people infected with both HIV and TB is rising and will reach four million by the year 2000. About half of TB patients in sub-Saharan Africa are also infected with HIV. In Tanzania, TB cases doubled between 1983 and 1991, a third of them related to HIV. In Asia, TB is already one of the most important life threatening opportunistic infections associated with HIV. In Europe and North America the rise in TB cases since the mid-1980s is due partly to HIV, but also to other factors such as increasing homelessness and poverty, and worsening public health systems

How do TB and HIV interact?

HIV and TB interact in several ways in individuals:

Reactivation of latent infection People who are infected with both TB and HIV are 25-30 times more likely to develop TB disease than people infected only with TB. This is because HIV stops the immune system working effectively and TB germs are able to multiply rapidly. In developing countries where many people are infected with TB and HIV, HIV-associated TB disease is very common.

Primary infection New TB infection in people with HIV can progress to active disease very quickly. In the USA active TB disease in two-thirds of people with both infections is due to recent infection rather than reactivation of latent infection. People with HIV are at risk of being newly infected if they are exposed to TB germs because their weakened immune system makes them more vulnerable.

Recurring infection People with HIV who have been cured of TB may be more at risk of developing TB again. However it is not clear whether this is because of reinfection or relapse.

In the community there are more new cases of active TB because more people infected with TB develop active disease, and those newly infected become ill faster. This means that there are more people in the community who are infectious to others.

Larger numbers of people with active disease means that more people will die from TB unless they are treated. Tuberculosis is now one of the leading causes of death in people infected with HIV. In Abidjan, Côte d'Ivoire, for example, a third of people with AIDS are thought to have died from TB. But TB mortality is only higher in people with HIV if it is untreated. HIV-associated TB can be treated effectively if people are diagnosed early and given proper treatment.

The association of TB with HIV means that people suffer additional discrimination. If a young adult develops TB other people may assume that they also have HIV. Health workers need to respect the confidentiality of TB patients in the same way as that of people with HIV, while also ensuring that communities and families know how to prevent its spread. TB in people with HIV is no more infectious than TB in people who do not have HIV.

Community education is needed to increase awareness that TB is curable and, most important, that people are no longer infectious after the first few weeks of treatment. It is essential to tackle the stigma and fear associated with both TB and HIV.

*Number of people developing active TB 1990 - 1993**

Source: WHO. Weekly Epidemiological Record, 1995, 70, 73-80.

*Average notification rates of new and relapsed TB cases

Principles of TB control

Proper detection and treatment

People can only spread TB to others when they have active TB disease. The key to TB care and prevention is to identify people who are infectious and to provide prompt and effective treatment to make them non- infectious and cure them

Case finding should prioritise identifying people with smear positive active TB because they are the most important source of infection in the community. Passive case finding means diagnosing infectious smear positive people who come to health facilities with symptoms of TB

Active case finding means trying to reach all those in a community who may have infectious TB disease. It is important to check children under five in a patient's family. However, in general active case finding is more expensive than passive case finding and studies have shown that fewer people may complete treatment.

Treatment and supervision

Anti-tuberculosis drug treatment is 95 per cent effective only when it is used correctly, so it is most important that TB patients complete their treatment. The treatment is based on a combination of drugs taken for at least six months, in two phases: an initial phase and a continuation phase. The combination of drugs varies as does the length of treatment.

People may find it difficult to take anti-tuberculosis drugs for a long period of time. But they can be helped by a well supervised programme and use of DOT (directly observed therapy) which means watching the person take their drugs. It is especially important that patients take their treatment during the initial phase to make them non-infectious.

BCG vaccination

BCG vaccine protects children against the most severe and life-threatening forms of TB disease in childhood, such as tuberculous meningitis. BCG does not reduce the risk of being infected with TB, and its impact on preventing pulmonary disease is limited. So BCG has a very restricted role in TB control because it does not prevent transmission of infection in the community.

BCG vaccination should be given to young children as early in life as possible, preferably immediately after birth. The only exception is if the mother is sputum smear positive when the baby is born. In this situation the infant should be given preventive therapy for six months. At six months a tuberculin test should be done. If it is negative BCG vaccination should be given.

Giving BCG vaccine to HIV-positive infants may increase complications or disseminated BCG disease (illness caused by the vaccine itself) in infants with severe immunodeficiency. However, the benefits of BCG vaccination outweigh the possible risks to HIV positive infants. Therefore BCG vaccine should be given to all infants, including those who may be HIV positive, and only withheld from infants with symptomatic HIV disease.

WHO/United

BCG vaccination protects children against TB disease in childhood.

Women and TB

TB is often more likely to be detected and treated in men than in women. Women and men may be equally affected but often fewer women seek treatment for reasons including

- lack of time because of work and family demands
- lack of money and transport
- the need to get permission or be accompanied by a male member of the family to a health centre
- stigma (some forms of TB can cause infertility)
- poor education which limits access to information about symptoms and treatment of active disease.
- lack of female health workers in cultures where female modesty is important

TB programmes need to be more responsive to the needs of women if they are to successfully increase case finding and treatment.

Source: Smith I. and Hudelson P. personal communication.

Preventive chemotherapy

Preventive therapy (or chemoprophylaxis) means giving anti-tuberculosis drugs to an individual with TB infection (or at very high risk of being infected) to prevent progression to active disease. In developing countries preventive therapy is only usually recommended for young infants whose mothers have active pulmonary TB, and children under five who are living with a person with infectious TB.

Chemoprophylaxis is also beneficial for individuals with HIV and TB infections, to preventing them from developing active TB disease. However, there are still many unanswered questions, and providing preventive therapy is not a feasible option for most national TB programmes.

Detection and diagnosis

Health workers should suspect TB if patients present with the following symptoms and history

Adults
- cough for more than three weeks
- blood in the sputum
- chest pain for more than one month
- increasing weakness and loss of weight
- had TB in the past or previously treated for cough

Children
- close contact with a smear positive case
- positive tuberculin test
- wasting — decrease in weight with no obvious reason
- two or more episodes of fever with no obvious cause such as malaria

TB treatment should not be started on the basis of clinical symptoms alone (unless non-pulmonary disease is suspected when immediate referral and treatment are very important).

The main diagnostic tools are:
- sputum smear microscopy
- culture of bacteria
- tuberculin skin testing
- chest radiography (x-ray)

Sputum smear microscopy

Sputum smear microscopy is the most useful diagnostic tool in low income countries. Sputum examination is cheaper, easier and more reliable than taking x-rays, more reliable than tuberculin testing, and cheaper and easier than culturing. It is possible to detect most smear positive cases of pulmonary TB using sputum smear microscopic examination.

The method of collection of the sputum is important. It should be produced away from other people, placed in a tightly covered labelled container and delivered to the laboratory as soon as possible. If TB is suspected, ideally three sputum specimens should be collected within 24 hours: during the first consultation; by the person at home the next morning; and at the second consultation.
- Two positive sputum smears are enough to confirm the diagnosis of TB.
- If the first smear is positive and the second is negative (or vice versa), a third smear needs to be examined.
- If the first smear is positive and the person does not return for the second consultation they need to be followed up and encouraged to return. Without treatment they will infect others and their own condition will get worse.
- Health workers in areas without smear facilities need to look for clinical symptoms and history suggesting TB and refer the person to a health facility for screening.
- One negative smear result is not enough to exclude a diagnosis of TB.

Smear microscopy requires well-trained laboratory workers and well-maintained equipment. Poorly trained staff or inadequate equipment can lead to over-diagnosis of smear negative and under-diagnosis of smear positive cases. Sputum smear microscopy is also used to check cure, which is based on smear conversion from positive to negative.

Culturing

A specimen of sputum is sent to a specialised laboratory where TB bacilli, if they are present, can be 'grown' or cultured. Culturing is more sensitive than sputum smear microscopy but in many countries facilities and personnel are not available. It is also expensive and the results can take several weeks to come back. This delays confirmation of the diagnosis and starting treatment. Culturing is therefore often inappropriate as a diagnostic tool but is used to test TB bacilli for drug resistance and sensitivity where a patient is not responding to treatment. Culturing is also used for sputum smear

Definitions

Sputum smear examination laboratory technique to screen sputum for TB, where acid fast bacilli (AFB) are stained red by the Ziehl Neelsen method, and then identified and counted using microscopy

Smear positive TB at least two initial sputum smears positive for AFB or one AFB positive smear and one positive culture

Smear negative TB at least three negative smears, but TB suggestive symptoms and x-ray abnormalities or positive culture

Adherence person takes appropriate drug regimen for required time (also known as compliance)

New case a patient with sputum positive pulmonary TB who has never had treatment for TB or has taken anti-TB drugs for less than 4 weeks

Relapse a patient who returns smear positive having previously been treated for TB and declared cured after the completion of their treatment

Failure case a patient who was initially smear positive who began treatment and who remained or became again smear positive at five months or later during the course of treatment

Return after default a patient who returns, sputum smear positive, after having left treatment for at least two months

Transfer in a patient recorded in another administrative area register and transferred into another area to continue treatment (treatment results should be reported to the district where the patient was initially registered)

Transfer out a patient who has been transferred to another area register

Cured initially smear positive patient who completed treatment and had negative smear result on at least two occasions (one at treatment completion)

Treatment completed initially smear negative patient who received full course of treatment, or smear positive who completed treatment, with negative smear at end of initial phase, but no or only one negative smear during continuation, and none at treatment end.

negative cases where active TB is suspected

Tuberculin skin testing

Tuberculin skin testing, which measures the body's response to TB, is also less useful in clinical diagnosis, except in children. An individual can produce a positive tuberculin test result if they are infected with TB or have been vaccinated with BCG. The tuberculin test cannot reliably differentiate between TB infection and TB disease. The test may also give a 'false negative' result if someone is infected with TB and HIV (see below).

Chest radiography

Chest radiography or x-ray is expensive and usually available only in hospitals. It is not the most reliable way of diagnosing TB, although it can be a useful supportive tool to help medical officers to diagnose smear negative TB. Chest abnormalities which show up on x-ray may be due to other conditions or previous TB disease. Relying on x-ray results can lead to over-diagnosis of TB and unnecessary drug treatment. But chest radiography may not detect the early stages of TB disease, and the signs of pulmonary TB (such as cavitations) usually seen on x-ray are less common in people with HIV.

Detection and diagnosis of TB in people with HIV

In most people in the early stages of HIV infection, symptoms of TB disease are the same as in people without HIV infection.

In areas where many people have HIV infection, TB programmes should continue to focus on identifying infectious sputum smear positive cases through microscopy. However, diagnosis of TB in individual patients using the standard diagnostic tools can be more difficult if they have advanced HIV infection.

- HIV positive people with pulmonary TB may have a higher frequency of negative sputum smears. Confirming the diagnosis may require sputum culture.
- The tuberculin skin test often fails to work in people who are HIV positive because it relies on measuring the response of a person's immune system. If the immune system has been damaged by HIV, it may not respond even though the person is infected with TB. HIV positive people with TB therefore have a higher frequency of false negative tuberculin skin test results.
- Chest radiography may be less useful in people with HIV because they have less cavitation. Cavities (spaces in the lungs) usually develop because the immune response to the TB bacilli leads to some destruction of lung tissue. In people with HIV, who do not have a fully functioning immune system, there is less tissue destruction and hence less lung cavitation.
- Cases of extra-pulmonary TB seem to be more common in people who are co-infected.

The health worker may suspect HIV infection because TB is difficult to diagnose, and the person is sick with other HIV-related infections. Offer confidential counselling and testing if available and appropriate. However, it is not necessary to know the person's HIV status.

Sputum smear microscopy is the best way to find out if a person has smear positive TB and is infectious to others.

For people thought, or known to have, HIV with TB symptoms:

- Screen for TB using sputum smear microscopy.
- If the result is positive start treatment.
- If the smear result is negative but it is suspected that the patient has TB. sputum culture should be carried where feasible to confirm the diagnosis.
- Give TB treatment to those with positive culture results.

Alternatively, where culture cannot be done, treatment can be given to those judged by a doctor to have active TB on the basis of x-ray and clinical symptoms.

Many HIV-infected smear negative patients thought to have TB in fact have other diseases. It is important to exclude the possibility of other infections before starting TB treatment.Usually this is done by treating first with a regular antibiotic for two weeks, and repeating the smear tests at the end of the two weeks if the person still has symptoms. If smear positive, start anti-TB treatment, but refer if still smear negative

Treatment for TB

27.1.2.

The principles of treatment are

- an appropriate combination of drugs to prevent development of resistance;
- prescribed in the right dosage;
- taken regularly by the patient under supervision;
- for a sufficient period of time.

Drugs The most commonly used first line anti-tuberculosis drugs are: isoniazid (H), rifampicin (R), ethambutol (E), pyrazinamide (Z), streptomycin (S), and thiacetazone (T). Some of these drugs are available in combined preparations, for example isoniazid with rifampicin (RH) and isoniazid with ethambutol (EH). Treatment regimens which contain both isoniazid and rifampicin are the most effective. Because rifampicin is such a useful anti-TB drug, its use in treating diseases other than TB should be carefully limited. It is important to supervise treatment regimens containing rifampicin

Pregnant women and young infants

- Pregnant or breastfeeding women who have TB should be treated with short course chemotherapy, regardless of HIV status.
- Rifampicin, isoniazid, pyrazinamide, ethambutol are safe for use in pregnant women.
- Streptomycin should not be given to pregnant women as it may cause deafness in the baby.
- If the mother has smear negative pulmonary TB at the time of birth the infant should be vaccinated as normal with BCG (unless she or he has HIV-related illness).
- If the mother is sputum smear positive at the time of birth and the infant is well, he or she should be given preventive therapy (isoniazid 5mg/kg in a single daily dose for 6 months) but not BCG. Give a tuberculin test to the infant after the six months preventive therapy. If the result is negative vaccinate with BCG.
- If the infant is unwell with TB symptoms give full anti-tuberculosis treatment.

Length of treatment Until recently the standard treatment regimen was 12-18 months. However, people are not likely to complete such a long course of treatment, which means they are not cured and continue to infect others in the community. Regimens can be shortened to 6-8 months if they include rifampicin. These regimens are called Short Course Chemotherapy (SCC).

Since the late 1980s WHO has encouraged national TB programmes to introduce SCC regimens which include rifampicin. Because of financial constraints many developing countries are still using the old standard 12 month course. However, the drugs for the short treatment course are only a little more expensive. Successful completion of treatment is also higher and better cure rates are achieved. This means that SCC regimens are a better use of resources. Whatever regimen is used, making sure that the person takes the full course is essential.

Treatment of people with smear positive TB should always include:

an ***initial intensive phase*** - in this phase a combination of four drugs is given daily, to eliminate as many TB bacilli as possible and prevent the development of drug resistance. The initial phase of therapy should be given for a minimum of two months and continues until the patient becomes smear negative. Most people will have become smear negative after two months of treatment.

a ***continuation phase*** - in this phase fewer drugs are given but the treatment needs to be continued for long enough (depending on the SCC regimen the continuation phase can be four or six months) to ensure that the patient is permanently cured and does not relapse after completion of treatment.

Some TB programmes are limiting the use of streptomycin because it has to be given by injection. This is more expensive and risks spreading HIV where it is difficult to guarantee proper sterilisation of needles and syringes. Thiacetazone is no longer recommended in areas where HIV infection is common because of side effects.

A young mother is treated for TB in her own home.

Intermittent therapy means taking anti-tuberculosis drugs three times a week instead of daily. There is no difference between intermittent and daily regimens in terms of the length of time before sputum conversion from positive to negative, or the final outcome.

How to assess cure?

To be sure that TB is cured, a patient who is initially smear positive must produce a smear negative result after treatment. The change from sputum smear positive to sputum smear negative is called smear conversion. Patients need to be followed up to ensure that information on sputum conversion and outcome of treatment is obtained.

The patient's sputum should be examined after the initial two months of treatment. If it is smear negative, they can start the continuation phase. The sputum should be examined again at the end of the fourth or fifth month to identify people who have failed treatment. During the last month of treatment a final smear is taken to identify cure, or treatment failure

Patients cannot be classified as cured if there is no sputum conversion from positive to negative. This applies to

initially sputum negative patients, or to sputum smear positive cases who completed treatment, with negative smears at the end of the initial phase, but with no or only one negative sputum examination in the continuation phase and none at the end of treatment. Sputum conversion is the only way to be sure that a person is cured, even if they complete treatment and have no clinical symptoms. If it is impossible to examine the sputum, then the patient is classified as 'treatment completed'.

Failure to respond

People fail to respond to treatment either because:

- they are not taking their drugs OR
- they have drug resistant TB.

Not taking the drugs is the most common reason for treatment failure. If a person continues to be sick, with persistent cough, fails to gain weight and has persistent positive sputum after treatment for some time, use the WHO recommended retreatment regimen for both HIV positive and HIV negative patients who:

- remain sputum positive after five months of treatment (failure case)
- interrupt treatment for more than 2 months and return smear positive (return after default case)
- return smear positive after completing treatment and being declared cured (relapse case).

The therapy for retreatment should be fully supervised for at least three months, and longer if the patient is still sputum smear positive after three months. If the patient still fails to respond they may have resistant TB bacilli and need to be referred.

REMEMBER:

- if a patient fails to respond to the treatment regimen, refer for assessment
- treatment should be supervised as poor compliance is even more likely with more toxic and longer regimens
- good record keeping is essential to distinguish between people with new active TB, or who have failed treatment, because the treatment regimens are different.

Source: Treatment of TB. Guidelines for National Programmes. WHO

TB SCC treatment for new cases, adults >50kg

INITIAL PHASE

2 months DOT

isoniazid and rifampicin H: 150mg, R: 300mg 2 tablets DAILY	AND	pyrazinamide Z: 500mg 4 tablets DAILY	AND	ethambutol E: 400mg 3 tablets DAILY	OR	streptomycin powder 1 g base in vial Injection DAILY

CONTINUATION PHASE

4 months DOT			OR	**not DOT** **6 months**	OR	**6 months DOT** **(not if HIV + risk)**
isoniazid and rifampicin H: 100mg, R: 150mg 4 tablets DAILY 3 x WEEKLY	AND	isoniazid H: 300mg 1 tablet, 3 x WEEKLY		isoniazid and ethambutol H: 150mg E: 400mg 2 tablets DAILY		isoniazid and thiacetazone H: 300mg T: 150mg 1 tablet DAILY

TB re-treatment for adults >50kg

INITIAL PHASE

3 months DOT — **First 2 months only**

isoniazid and rifampicin H: 150mg, R: 300mg 2 tablets DAILY	AND	pyrazinamide Z: 500mg 4 tablets DAILY	AND	ethambutol E: 400mg 3 tablets DAILY	AND	streptomycin powder 1 g base in vial Injection DAILY 750mg

CONTINUATION PHASE

5 months DOT

isoniazid and rifampicin H: 100mg, R: 150mg 4 tablets DAILY 3 x WEEKLY	AND	isoniazid H: 300mg 1 tablet, 3 x WEEKLY	AND	ethambutol E:400mg 4 tablets 3 x WEEKLY

Side effects of drug treatment

Serious side effects to TB drugs are rare. Minor side effects do not mean that treatment should be stopped, but people need reassurance and to be warned about possible side effects in advance. Side effects which are associated with certain drugs include:

- **Skin rashes and itching** - reaction to thiacetazone and other drugs.
- **Shock and fever** - can be caused by rifampicin, pyrazinamide and/or streptomycin.
- **Problems with sight** - can be caused by ethambutol. Patients should be warned to report any problems with their vision. Ethambutol is not usually given to children who are too young to be able to report visual problems.
- **Hepatitis** - liver disease where the patient develops jaundice. Commonly due to isoniazid but may also be caused by rifampicin and pyrazinamide.
- **Dizziness** - caused by streptomycin, most frequently in older individuals or children Streptomycin should never be given to pregnant women because it can cause deafness in the unborn child.
- **Reaction in the joints** such as pain, swelling, heat - caused by pyrazinamide.
- **Flu-like illness and/or abdominal pain** - caused by rifampicin.
- **Red/orange colour of body fluids** such as tears or urine - caused by rifampicin.

If patients develop any of the following serious side effects stop the treatment and refer them to a doctor immediately:

- yellow jaundice
- serious skin conditions (more common in people with HIV)
- problems with urinating and possible renal failure
- shock

Community and home based care strategies for TB and AIDS

AIDS and TB in Asia

As AIDS cases rapidly increase in Asia, many countries turn towards community- and home-based care for people with HIV and AIDS. The AIDS pandemic also has considerable implications for existing TB control programmes in Asia, which has the highest number of TB cases in the world. For TB control, Direct Observed Treatment with short course Chemotherapy (DOTS) is a widely advocated and accepted strategy. AIDS and TB care strategies are closely linked, with people in the community and family providing care and support. The linkage is even stronger, as the two diseases are often found together in the same patient.

There are also fundamental differences between HIV/AIDS and TB control strategies. Especially when it comes to prevention, AIDS control focusses mainly on behaviour change, whereas TB prevention is best achieved through treatment and cure. As a result of this, TB programmes are more usually combined with leprosy programmes, and AIDS integrated with STD or family planning. At the level of the health services, it is rare to find combined TB/AIDS programmes.

TB and HIV are often integrated at the patient level, as far as needs for care and support are concerned. To what extent then do treatment, care and support strategies for the two conditions relate?

Integrated care and support for TB and AIDS

Two questions are important if we explore the possibilities of integrating TB and AIDS care. For health service planners, the following questions are relevant:

1. Can planning for home-and community-based care for people with HIV/AIDS (PWA) learn anything from care for patients with TB, and vice versa?

For health workers and care-givers, the practical implications of service delivery will be more relevant:

2. How can we integrate HIV care into the DOTS strategy for TB patients, and conversely, how can we provide proper treatment for TB through existing AIDS care systems?

Planning for integrated TB and AIDS care: learning from each other

1. DOTS: TB care and support:

In the past, most TB patients used to be hospitalised, but recognition that TB could be treated at home without putting the family and community at risk led to ambulatory treatment. Promotion of 'supervised treatment' reintroduced hospitalisation, but the heavy burden on the health care systems, forced a reversion to community based treatment.

DOTS, a community-based TB treatment and care strategy, combines the benefits of supervised treatment, and the benefits of community-based care and support. It ensures high cure rates in patients with tuberculosis, through its three components: appropriate medical treatment, supervision and motivation by a non-health worker, and monitoring of disease status by the health services.

Short Course Chemotherapy is a combination of anti-tuberculosis drugs, for a sufficient period of time.

Supervision and motivation by a person who is accessible to the patient and accountable to the health service, encourages and educates the patient, and observes them taking their medicines correctly.

Monitoring of the patient, to determine the outcome of their treatment.

2. Home and community based care and support for people with HIV/AIDS:

In many resource-poor countries, the health services have been overburdened with the care for people with HIV/AIDS. The realization that long term hospitalization is rarely needed for adequate treatment of opportunitic infections, and that there are rich traditions of community support for chronic patients, led to the development of home- and community-based care and support strategies. In Asia, initiatives often come from community-based and AIDS service organisations, to be taken on later by government health services.

Care and support programmes for people with HIV/AIDS advocate a 'continuum of care', from national hospitals through health posts, communities, and families to individuals. The components are not only medical and nursing care, but also social, emotional, spiritual, and material support. AIDS requires a long term commitment, till death. HIV prevention education for patients and their carers is necessary, and closely linked to care.

3. Combining the strengths:

The similarity between the two approaches is the idea of shared care, shared responsibilities. Through linking person, both aim to support the patient in maintaining independence and responsibility, while avoiding to make him/her solely responsible for provision of care

AKAP

Both acknowledge the important roles of the care giver, as advocate on behalf of the patient, and health educator to community. The challenge for both programmes is to avoid overburdening women and girls, the traditional care givers.

However, the approaches differ in their perspective. Underlying DOTS is a medical approach, the emphasis is on appropriate treatment and cure. DOTS is unique in that it explores ways to strengthen patient support and motivation in order to achieve cure. On the other hand, care for PWAs is a more holistic approach, with an emphasis on care and support, by lack of a cure for AIDS. The strength is its perspective of the patient, and the challenge is to strengthen its medical care, and cure, component at community level, not least for TB as an opportunistic infection. Interestingly, both approaches meet at the level of the family and community, and acknowledge the need for and strengths of traditional, holistic health care.

Home based care of PWAs is an NGO dominated field, whereas TB care is mostly a government health service initiative. Health services are often better at providing medical services, NGOs often better at providing care, enabling and empowering. The 'continuum of care' concept, acknowledges the necessity to link public and private health services. In many PHC programmes, community health workers play this pivotal role, sometimes leading to heavy demands on their time. The challenge for TB programmes is to involve community-based groups as supervisors and educators, and the challenge for HIV/AIDS programmes is to involve local health personnel.

Implementation of integrated care and support

It is obvious that it is necessary, and possible, to integrate home and community-based care and support for people with TB and/or AIDS. However, it requires a concerted effort from policy makers at national level, health workers, and caregivers. The following recommendations could provide a supportive environment for people with TB, HIV, or both, and could lead to appropriate, humane, and effective care.

Recommendations for National TB programmes:

- Coordinate with National AIDS Progamme
- Training TB workers/health workers in AIDS, recognizing opportunistic infections, counselling and confidentiality, universal precautions, etc.
- Develop national policy on testing with emphasis on confidentiality
- Develop national policy choice of treatment, and Isoniazid preventive treatment

Recommendations for health workers:

- Treat every TB patients as if he/she is HIV+: universal precautions
- Provide diagnosis and treatment services for TB as close to home as possible
- Create linkages and referral systems with local AIDS NGOs
- Counsel known HIV+ patients, or refer to AIDS NGOs
- Educate all TB patients and caregivers on HIV/AIDS prevention
- Strengthen follow up for re-infections relapses
- Select caregivers carefully, support them, be aware of burn out, impact on wives/daughters, refer to AIDS support NGOs
- Providing treatment for TB through community-based AIDS care systems

Recommendations for National AIDS programmes:

- Coordinate with National TB Programme on training needs for health workers and policies on testing and counselling
- Strengthen TB control programs

Recommendations for local health worker and AIDS support workers:

- Teach PWAs/caregivers **before they get TB** the importance of full treatment
- Teach PWAs/caregivers to recognize TB symptoms early, and seek treatment
- Diagnose TB early, and treat TB appropriately, or build link with TB treatment centres
- Provide support not only to the patient, but also to the caregivers, prevent burn out

Recommendations for caregivers:

- Know the symptoms of TB, encourage early diagnosis and treatment
- Supervise medication in case of TB

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by Ian Smith, Paul Janssen and Sally Smith
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DOTS, TB and HIV

DOTS is the latest of health-related acronyms to hit the media. Standing for Direct Observed Therapy Short-term, DOTS is touted as ***the*** way to controlling, if not eradicating, the age-old problem of tuberculosis through closely supervised treatment for six to eight months. Considering that the re-surgence of tuberculosis has come partly as a result of a newer public health problem, HIV/AIDS, it is important to look at how DOTS will impact on health care strategies in general.

DOTS and Compliance

The whole rationale of DOTS is based on patient non-compliance with the prescribed treatment. DOTS therefore calls for supervised treatment. But just what is this problem of compliance? DOTS was first developed in the United States, in settings of "stubborn" patients such as drug dependents who would not comply with the doctors.

In many situations in developing countries, the problem is not so much of patient compliance than access to TB drugs. In the Philippines, for example, the prescribed course for six months costs P6000 (US$230), equivalent to about two months household income in many impoverished rural villages.

If the drugs are available for free or at subsidized costs from the government or non-government charities, they are still often limited to town centers. In fact, promoting DOTS may reinforce the idea that the medicines should be dispensed only in areas where qualified health professionals are available to supervise treatment. This again places severe limitations on access: the people most vulnerable to tuberculosis also being the people who cannot access health centers because of physical as well as financial reasons.

Access, one forgets, is often socially determined. Thus, even in urban poor areas, government health centers may be physically accessible yet considered socially distant because of impersonal staff, or because of the stigma attached to TB. DOTS in fact has the potential of further stigmatizing the disease because of its having to be treated by health professionals in institutional settings.

Even if medical supervision were available and accessible, we deal now with a wide range of factors that affect a patient's use of TB medications. There are many possible side effects, even adverse reactions, that can result from the medicines. Paradoxically, the positive effects of TB medication may also lead to patient drop-out from treatment. Once the patient feels better — and this can occur even within the first two weeks after treatment begins — he or she might stop taking the medicine.

Of course, one could argue that DOTS has a role here in explaining both positive and negative effects of the medicines. This presumes that health personnel will provide support in explaining the effects and assuring patients and their families when adverse reactions occur. DOTS probably will work if implemented by highly motivated community-based health personnel. Unfortunately, in many situations — both in developing and developed countries — such personnel are hard to come by, given the already loaded public health systems.

Learning from TB

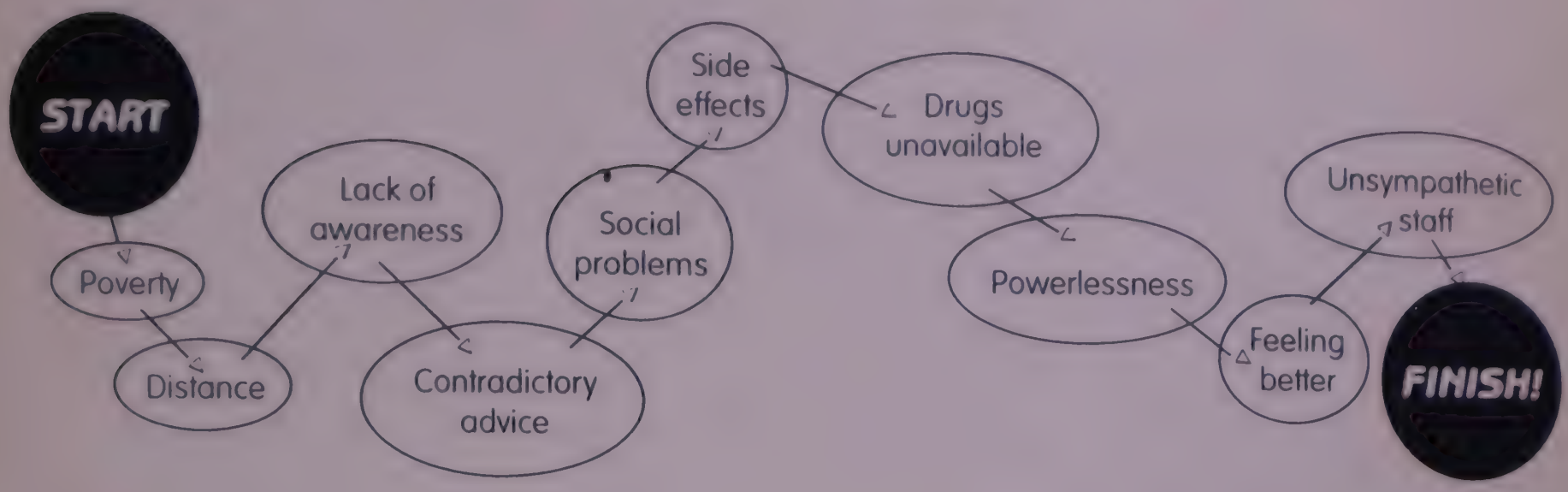
DOTS actually represents a revival of old public health models, what some have called the medical police model with an emphasis on surveillance, patient tracking and institutional settings. It is ironic that DOTS is being promoted at a time when the HIV epidemic has resulted in alternative models: highly decentralized and community-based. No doubt, DOTS could adopt many aspects of community-based health care. AKAP, a Filipino non-government organisation doing primary health care, demonstrated this more than a decade ago in an urban poor resettlement area, challenging the dominant model at that time of sanitarium care. Community health workers fanned out for both preventive (health education, immunization) and curative services, including what one could call DOTS today. But such programmes received little support. One would have to be extremely cautious in predicting the prognosis of DOTS today, the way it is promoted and implemented through the aegis of centralised government bureaucracies.

Perhaps even more disturbing is the way DOTS focuses on a curative drug-centred model for eradicating TB. One forgets that TB was eradicated in much of the developed world long before TB medicines were discovered, or that TB remains a major problem in many poor countries decades after drugs and vaccines were discovered, or that the resurgence of TB is happening with socially marginalized and deprived communities — ethnic minority groups; refugees; urban poor — both in developed and developing countries.

Drugs do have a place in TB eradication, and the problem of drug resistance — because of improper use of TB medicines — is only too real. Unfortunately, DOTS places too much emphasis on patient non-compliance, failing to recognise that even problems of drug resistance came out of the medical establishment's indiscriminate prescribing and dispensing. (Or, in countries like the Philippines, from politicians' dispensing of a week's supply of free anti-TB drugs.) There is the danger that DOTS will reinforce false expectations about what pharmaceuticals can do. If anything, TB has taught us that medicines and vaccines alone will not bring automatic solutions. Prevention through education will always remain vital. It is a lesson one must keep in mind in relation to TB's modern-day counterpart: HIV/AIDS.

M.L. Tan
HAIN

TB treatment game



This game aims to help health workers explore why people might stop taking their TB drugs. It can be played by individuals or small groups, playing against each other.

Players have to try to cross the TB treatment river, using the stepping stones. If they reach the other side they have completed their treatment and are cured. However, there are many reasons why they might slip off the stones, and fail to take their drugs.

1. Ask participants to describe a health worker's typical reaction to someone who stops treatment — often anger and frustration. Then ask them to think of all the reasons why people with TB might not complete treatment, and to pick out the 10 most important ones.

2. Hand out copies of the game with the stepping stones left blank, and ask participants to write in the 10 reasons.

3. Draw a circle about 50cm in diameter on the floor, and divide into 6 equal wedges. Write the numbers 1 to 6 in the wedges. Draw a boundary line 2-3m away from the centre of the circle.

4. The player stands behind the boundary line, and throws a coin into the circle. If the coin lands inside a wedge, then the player moves across that number of stepping stones. If the coin lands outside the circle, or on a line, then the player has fallen off the stone, and is out. If the first throw is out, allow the person to throw again until they land in a wedge and reach a stone. Each person continues throwing until they reach the other side or fall off a stone.

5. Discuss the game with participants:

- How many people fell off? Is this figure similar to the proportion who don't complete their treatment?
- Which stones did people fall off most — are these common reasons in real life?
- Of the reasons given, for which can the person be blamed? And the health worker? Is it fair for health workers to be angry with people who default?
- How can health workers encourage people to complete their treatment?

Usually only one or two reasons are the person's fault, and the rest are the health service's responsibility. Finish by asking whether in fact it is the patient who should be angry with the health worker, rather than the other way around!

Another useful exercise is to ask the health workers, in small groups, to draw a TB patient. Pin the pictures up and use them as a discussion starting point. Ask questions such as: What signs and symptoms do the pictures show? What kinds of people have they drawn? Health workers often draw a picture of an adult man. Ask: Does this mean that health workers are less likely to consider TB in women?

Source: Smith I. Tuberculosis control learning games. Tropical Doctor, July 1993 and personal communication

Ways to work together: HIV and

TB control requires a well organised national programme. A poor programme is worse than none at all, because of the risk of large numbers of people being given inadequate treatment. This means they will continue to be infectious to others and this can lead to the development of TB strains resistant to available drugs. WHO and IUATLD (the International Union Against TB and Lung Disease) have developed standard guidelines for national TB programmes, which are responsible for planning, policy, budgets, supervision and training. An effective programme needs:

- a **recording and reporting** system that provides information about case categories and treatment results
- to **train staff** to screen, diagnose and treat patients
- a reliable sputum smear **microscopy service**, with adequate equipment and trained laboratory personnel
- **treatment services** which provide directly supervised short course chemotherapy and health education
- a **reliable supply of drugs and diagnostic materials.**

TB programme activities

(showing possible links with HIV services)

Central TB unit, MOH
- plan, monitor and supervise national activities
- liaise with HIV/AIDS/STD and essential drugs programmes
- co-ordinate training, drugs and diagnostic supplies

Regional TB co-ordinators
- liaise with central TB unit
- ensure effective co-ordination of above activities in region, and liaise with HIV services
- regular technical supervision of district TB officers
- review case finding and treatment reports

District TB officer (with DMO)
- supervise and visit primary facilities
- collect data for and maintain district TB register, with quarterly reports on new cases, relapses and treatment results
- support case finding activities
- supervise effective microscopy service and records
- arrange training and supervisory activities, including HIV-related issues
- ensure referral possible if necessary
- maintain drugs and equipment
- **make appropriate links with district AIDS committee and AIDS team at hospital**
- **encourage community education and links with AIDS NGOs providing home care and education**

Primary health facilities
- identify people with possible TB symptoms and trace contacts
- take sputum samples and liaise with laboratory
- provide efficient referral and treatment services: appropriate regimens and sputum testing, **counselling, health education, local organisation of DOT (clinic visits, community workers, AIDS home care services)**
- keep TB treatment cards and records up to date
- follow up defaulting patients and discharge patients who are cured or have completed treatment
- **carry out community education (with HIV services if appropriate)**
- report regularly to district level
- **ensure staff understand HIV and TB links, and are aware of needs for counselling etc.**

A TB programme should facilitate links between primary, district, regional and national levels and with HIV/STD programmes too. Health workers should always follow national TB programme guidelines. If there is no functioning TB programme in your area, use WHO TB treatment guidelines

Collaboration between TB and HIV/AIDS programmes

People with HIV and TB face similar problems of stigma and fear, and have needs for care and support, and for counselling and confidentiality. Closer collaboration between TB control and AIDS programmes in these areas could be useful. For example, more integrated approaches to community education could help to change attitudes to both infections and reduce stigma. Collaboration in home care and follow up of patients with TB and with HIV/AIDS could help to increase adherence to TB treatment and identification of people with active TB.

- Nurses in Kenya, trained in HIV counselling and who plan care for people with AIDS after discharge from hospital, are extending their services to patients on TB wards.
- In Ghana a peer support group for people with HIV, working with health staff, discusses TB prevention, early TB recognition, and treatment adherence during home visits
- Hospital community outreach teams in South Africa visit people with HIV and TB at home. Many patients have both infections and the integrated approach helps to share limited resources such as transport, to reduce stigma and to increase community acceptance.

What can NGOs do?

NGOs should make sure that their activities complement the national TB programme and discuss what role they can play to support the national programme with the district TB officer. Local AIDS organisations are playing a vital role in community education and care including:

TB programmes

- Ensuring that community members recognise TB symptoms, and understand that it can be cured
- Encouraging people with symptoms including those who may have HIV to be screened for TB and to seek treatment
- Encouraging people to take their treatment using DOTS systems
- Countering misbeliefs and stigma about AIDS and TB
- Educating people about the ways in which TB is spread and encouraging them to cover the mouth when coughing and to spit into a container and dispose of sputum carefully
- Providing home care and support to people with TB and HIV.

What can health workers do?

Health workers need to be friendly and aware of the person's needs for confidentiality, and to:

- Ask about symptoms — if a person has had a cough for more than three weeks and chest pain, get a sputum test done
- Make sure that the person understands that the full course of treatment is needed even if the symptoms soon go, and discuss the person's fears and worries about TB (and HIV)
- Be aware of the possibility that the person may have HIV, and offer HIV counselling and testing if it is appropriate and available
- Help them to take their full course of treatment
- Make sure they understand that they are no longer infectious after 2-3 weeks
- Examine family and household contacts for TB, especially if they are ill
- Keep proper records and visit the person at home if they don't come for their appointment or drugs
- Ensure that supplies of anti-TB drugs are available and do not run out
- Refer difficult cases to a centre with a physician or TB specialist
- Check HIV patients for TB and make sure that people with both infections do not receive thiacetazone.

Community-based education programmes on TB could be broadened to include HIV/AIDS.

Keeping records

Records are needed for a TB programme to work effectively. The recording system should enable health workers and TB programme staff to plan, monitor and evaluate services and drug supplies and to:

- see how many cases are being detected
- ensure that all potentially infectious cases are being properly screened
- monitor patients' progress and adherence to treatment
- make sure all patients are fully treated
- assess the effectiveness of treatment
- distinguish new cases from those that have previously received treatment
- prevent the development of drug resistance
- identify problems and where more training or supervision is needed

For each person records need to be kept of:

- diagnostic examinations
- treatment including the initial phase of treatment, patient adherence and follow up
- follow up sputum smear results, smear conversion and treatment outcomes for those initially smear positive

A record system usually includes the following:

- patient TB card (kept by the person)
- TB treatment card (kept at the health facility)
- clinic TB register (kept at the health facility)
- TB laboratory register
- district TB register

Preventive therapy

TB chemoprophylaxis means treating people with symptomless TB infection to prevent the development of active disease. Preventive therapy has been shown to be beneficial for people with both TB and HIV infections who are at risk of rapid progression to active TB disease. Daily isoniazid (isoniazid preventive therapy or IPT) can reduce the incidence of active TB in HIV positive people. Before IPT can be considered, voluntary HIV counselling and testing facilities need to be available for people who may have HIV.

There are still many questions about IPT. It is not clear at what stage of HIV disease chemoprophylaxis should be given, or which drug regimens might be most effective. It is also not clear for how long people should continue to take preventive therapy and whether the benefits continue after completing the recommended period of therapy.

Who should get IPT?

IPT should only be given to HIV positive people who have TB infection but who do not have active TB. Those with active TB need full treatment. Giving only one drug to a person with active TB can help resistant strains of TB to develop.

Proper TB screening is essential to ensure that preventive therapy is not given to patients with active TB. But it is not always easy to confirm whether HIV positive individuals have active TB disease or TB infection (see page 5).

The WHO guidelines for tuberculosis preventive therapy in HIV positive individuals should be followed (see below). The guidelines emphasise that IPT should only be considered for HIV infected people with a positive tuberculin skin test who do not have active TB.

Limitations of IPT

Resources In most developing countries, voluntary counselling and testing for HIV, screening all HIV positive patients for TB infection, and providing drugs for preventive therapy are not possible. Although IPT can prolong healthy life in individuals with HIV and TB infections, resources should be prioritised for identifying and treating smear positive patients

Side effects Hepatoxicity (the risk of hepatitis) is one of the most common side effects of IPT and can be fatal. The risk is higher in adults aged over 35 years. However in HIV positive people the benefits of IPT generally outweigh the risk of toxicity, except in people with chronic active hepatitis or possibly those with more advanced HIV disease.

Drug resistance Preventive therapy could potentially increase drug resistance if it is wrongly given to those who have active TB. The effects on the development of drug resistance of large scale preventive therapy with one drug are not known.

Adherence Without good support and supervision, there may be problems in ensuring people take preventive therapy for long periods of time, especially if they do not have symptoms of TB disease.

WHO recommendations

1. Isoniazid preventive therapy can be of value to individuals with both HIV and tuberculosis infection.
2. Education about TB and its link to HIV infection should be part of HIV pre- and post-test counselling.
3. People who are HIV positive:
   - should be screened for TB by clinical examination.
   - should receive a tuberculin skin test.
   - if the tuberculin test is positive they should receive a chest x-ray.
4. People with symptoms consistent with tuberculosis and/or an abnormal chest x-ray should have sputum collected for bacteriological examination culture.
5. People with a positive skin test in whom active TB has been excluded (by x-ray and culture) should be given isoniazid at the daily dose of 5mg/kg up to a maximum of 300 mg for 6-12 months.
6. Persons receiving preventive therapy should be monitored monthly for adherence, toxicity and the development of active TB.

Source: Preventive therapy for TB in HIV-infected persons, Lancet vol 345, 1995.

Drug resistance

Drug resistance means that certain strains or types of TB bacilli are not killed by the anti-tuberculosis drugs given during treatment. Some strains can be resistant to one or more drug. WHO defines a multi-drug resistant (MDR) strain as one that is at least resistant to isoniazid and rifampicin. A person infected with MDR TB will therefore not be cured by short course chemotherapy which relies on these two drugs.

Why does drug resistance develop?

Drug resistance is caused by inadequate TB treatment and poor TB control programmes. The most common reasons for the development of resistance are:

- incorrect prescription
- irregular supply of drugs
- lack of supervision and followup

There are two types of drug resistance:

Acquired resistance is where resistance develops as a result of inadequate treatment. Use of a single drug is the most important cause of acquired resistance. This is because some TB bacilli are naturally resistant to anti-TB drugs. If a single drug is used to treat a patient who is infected with a large number of TB bacilli only those which are sensitive to that drug are killed, allowing the resistant bacilli to multiply. This is the reason for using several drugs during the initial intensive phase of treatment, until the number of bacilli has been greatly reduced.

Primary resistance is when an individual is infected by someone who already has drug resistant TB bacilli. The newly infected person will have TB that is drug resistant from the outset. The number of people with primary resistance — who

have drug resistant TB but who have not been treated for TB before — is increasing

Is MDR TB a major problem?

In all countries and especially those where the number of cases of TB is rising rapidly because of the association with HIV, the development of resistant strains of TB is a serious concern.

Between 50 and 100 million people worldwide are thought to be infected with strains of resistant TB. An accurate picture of drug resistance is not available because few countries have a reliable drug resistance surveillance system. Resistance varies, for example in Africa resistance to isoniazid is estimated at between 5 per cent and 10 per cent.

Resistance to rifampicin, one of the most effective TB drugs, is thought to be low in Africa because the drug has not been widely available. But there are signs that resistance to rifampicin is developing: for example, it has been reported in Thailand. Drug resistance is potentially a serious problem in countries where prescription of anti-TB drugs by private physicians is not well controlled.

WHO and IUATLD have developed guidelines to help countries detect strains resistant to the main TB drugs through national surveillance programmes. Better information will help countries to decide which is the most appropriate SCC drug regimen and the best strategies for retreatment.

What are the dangers of MDR TB?

The most serious danger is that MDR TB is much more difficult to treat, even where second line drugs are available. Treatment of MDR TB can take at least two years and the results are poor. Second line drugs cost 30-35 times as much as drugs used in SCC treatment of non-resistant TB. Patients with MDR TB may need to be hospitalised and isolated, which adds to the cost of treatment, to prevent transmission of primary resistant strains to others. In the USA it is estimated that treating one case of MDR TB costs ten times as much as treating a case of TB sensitive to the usual drugs. Careful precautions are necessary to prevent transmission, especially to health workers caring for MDR TB patients.

Checklist for IEC Activities on HIV/AIDS

(This checklist was developed by the Philippine National AIDS Council, and is based on the IEC Guidelines featured in *AIDS Action* issue 29.)

The Checklist is designed to help organisations evaluate their own materials and activities and to determine whether these conform with the principles stated in the IEC Guidelines.

The following IEC materials/activities may be evaluated using the IEC Checklist print - newsletters, news reports, brochures, posters, leaflets, hand-outs, flyers, billboards, T-shirts, and others; electronic/broadcast - radio, TV, film and video; interpersonal communication - counseling, workshops, lectures, focus group discussions, etc.

The Checklist is composed of 32 questions, marked "R" or "O". "R" means that a material/activity is required to comply with that particular question. Failure to comply with even just one required item means that the material/activity is not in accordance with the PNAC IEC guidelines. Questions marked "O" mean optional compliance. Although a material/activity does not have to comply with "O" questions, compliance with these would contribute to the improvement of the material/activity.

Organisations producing materials or conducting IEC activities are to evaluate their own materials using the chcecklist. As with the IEC guidelines, the checklist is recommendatory in nature — meeting the standards set by the PNAC is not compulsory. However, compliance with the checklist would contribute to a more effective IEC material/activity.

DEVELOPMENT OF THE MATERIAL

R. 1. Was baseline research conducted to identify knowledge gaps and attitudes and behaviors which may increase risk of HIV infection?
R. 2. Was a pre-test conducted with a group similar to the intended audience before the material was finalized?
O. 3. Did a panel of experts review the material before it was finalized?
O. 4. For materials which are to be translated into other languages, was back translation carried out to ensure that the translation is true to the original version?

ACCURATE

R. 5. Is biomedical and technical information in the material/activity consistent with empirical evidence of the World Health Organisation, or the Department of Health, or other recognized scientific bodies?
O. 6. Are bibliographical references or technical experts cited to establish accuracy of information presented?

CLEAR (text, illustrations, the material as a whole)

Does the material/activity:

R. 7. Convey simple and easy-to-understand messages?
R. 8. Use concrete terms (not abstract terms)?
R. 9. Use familar terms instead of jargon?
0. 10. Explain in a chronological sequence (when applicable)?
O. 11. Emphasize important points?

APPROPRIATE

Is the material/activity appropriate to the target audience in terms of:

R. 12. text?
R. 13. illustration?
O. 14. format?

ACCEPTABLE

R. 15. Does the material/activity avoid words, illustrations of messages which are considered or distasteful by the target audience?

GENDER SENSITIVE

R. 16. Does the material/activity avoid portraying any gender as being responsible for the spread of HIV? (This can be conveyed either in the text or in the illustrations)?
R 17. Does the material/activity avoid portraying women (in text or in illustrations) as mere sex objects?

EVALUATING HIV/AIDS ACTIVITIES

(continued from page 15)

O 18. Does the material/activity encourage empowerment of women to enable them to negotiate for safer sex practices?
O. 19. Does the material/activity promote positive attitudes toward the equality of men and women?

AFFIRMATIVE
R. 20. Does the material/activity avoid fear arousing messages?
R. 21 Does the material/activity avoid coercive messages?
O. 22. Does the material/activity specify desired behavior clearly?
O. 23. Does the material/activity emphasize efficacy of preventive behavior?

NON-MORALISTIC AND NON-CONDEMNATORY
R. 24. Does the material/activity avoid portraying any group (such as OCWs, homosexuals, injecting drug users, etc.) as being responsible for the spread of HIV/AIDS?
O. 25. Does the material/activity avoid condemning any population group for the behavior vis-a-vis HIV/AIDS?

NON-PORNOGRAPHIC
R. 26. Does the material/activity aim to educate and enlighten?
R. 27. Does the material/activity avoid prurient messages?

ON USE OF ILLUSTRATIONS AND PHOTOGRAPHS
R. 28. Use relevant illustrations / photographs?
R. 29. Convey a clear message through illustrations and/or photographs?
O. 30. Place illustration/photograph near relevant text?

DISTRIBUTION MECHANISM
R. 31. Does the material identify the audience for whom it was developed?
O. 32. Is there a "descriptive clause" in the cover of the material which gives an indication of its content?

RESOURCES

Clinical tuberculosis provides practical information on all aspects of TB control and clinical care. *Available for £3.00 in English, French, Spanish and Portuguese from from TALC, PO Box 49, St. Albans AL1 4AX, Herts, UK.*

Tuberculosis guide for low-income countries is a handbook providing information for staff involved in primary level prevention and care. *Single copies in English, French or Spanish free from IUATLD, 68 Boulevard Saint-Michel, 75006 Paris, France*

TB and HIV Quarterly: SidAlerte Supplement is a quarterly magazine in French and English covering good policy and practice in TB and HIV care and prevention. *For subscription details write to SidAlerte Internationale, 7 rue du Lac, 69003 Lyon, France.*

China Tuberculosis Control Collaboration. **"Results of Directly Observed Short-Course Chemotherapy in 112,842 Chinese patients with Smear-Positive Tuberculosis."** *The Lancet.* Feb. 10, 1996 (v. 347, pp 358-362).

Childhood TB is a new briefing paper from AHRTAG. *Available free to readers in developing countries.*

Preventing infections in health-care settings provides practical guidelines on reducing the risk of blood and air-borne infectoins. *Available free to readers in developing countries and for £5.00 elsewhere, from AHRTAG.*

Tuberculosis and AIDS : the situation in Asia by Garance Upham provides a summary of country reports presented in the 1993 TB and Respiratory Disease of the IUATLD, Eastern Region conference. *TB & HIV* Ja-Mr 1994 (10-11). *Free copies for developing countries may be obtained from **HAIN**.*

Country reports on HIV/AIDS: Pakistan, Cambodia, Vietnam. *TB & HIV* Ja-Mr 1994 (12-17). Free copies for developing countries may be obtained from ***HAIN.***

Please write to AHRTAG if you would like full list of the reference materials used for this special TB and HIV issue.

Articles were written by Kathy Attawell, with contributions from Dr. ET Maganu, Dr. Rumisha, Dr. Ian Smith, Dr. David Wilkinson, Patricia Hudelson, S Chondoka, P. Bwalya, Esther Sumatojo and others credited in text. AA takes full responsibility for any inaccuracies in the text.

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MATERIAL ON HIV/AIDS

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HIV, drugs and diet

BMC / HAIN

Eating well is important for maintaining good health and is an essential part of care for people with HIV.

Articles in this issue of ***AIDS Action*** highlight two areas of interest for people living with HIV or AIDS and those involved in caring for them — nutrition and anti-HIV treatments.

The article on pages 2 and 3 summarises new developments in treatments for tackling HIV. The author emphasises that, although researchers are making some progress, fully effective and affordable drugs against HIV have not been developed yet. Prevention and treatment for common opportunistic illnesses are still the most important strategies against HIV, especially now that TB causes more deaths in HIV-positive people than any other infection.

Good nutrition also plays a major role in maintaining health (see pages 4 and 5). It is often possible to make low-cost meals that are more nutritious, tastier and easier to eat for people who are unwell.

The article on pages 9 and 10 looks into the essential drugs for HIV infection, while page 8 explains how these drugs work. This issue also features an educational game which is popular in Chile, and which could be adapted for use in other languages and situations.

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Contribute to AIDS Action

Future topics include practical strategies for promoting people's rights; blood safety and infection control; ideas for integrating HIV into community development and education; planning, monitoring and evaluation techniques; traditional medicine; working with young people and children; and counselling.

Please send articles describing successful activities and approaches to HAIN.

Slow progress against HIV

We are still a long way from discovering a 'cure' for HIV infection. ***AIDS Action*** *highlights problems in developing new treatments.*

There are three types of treatment for people with HIV. These aim to:

- prevent the virus from reproducing
- strengthen or 'boost' the immune system
- cure opportunistic infections.

Anti-HIV treatments

One type of anti-viral drug aims to prevent or slow down viral reproduction in human cells (see box below). The drugs have a similar chemical structure to human DNA. This means that the virus bonds with the drug rather than the DNA, and so cannot use the DNA to reproduce itself.

The most widely used anti-viral drug is still AZT, or zidovudine. AZT has been in use since 1985 and is manufactured by Wellcome, under the brand name of Retrovir. Its benefits are limited when taken alone. The 1993 Concorde trial showed that AZT does not benefit people who are still healthy.

A number of other anti-viral drugs have been licensed in different countries for use alone (monotherapy) or in combination with AZT (combination therapy). They include ddI (didanosine), ddC (zalcitabine) and d4T (stavudine).

In September 1995 an international drug trial called Delta proved that a combination of anti-viral drugs is much better at delaying the development of HIV-related infections and death than AZT alone. The two-year trial compared the health status of people with HIV taking 'combination therapy' (AZT plus ddI or AZT plus ddC) with another group taking AZT alone. Ten per cent of participants were women.

Results show that, compared with taking AZT alone, the likelihood of dying for people taking combination therapy was reduced by almost 40 per cent. The benefits were greatest for participants who had never taken an anti-viral treatment before. However, disease progression was not affected for those starting combination therapy after taking AZT alone for several months.

Pregnancy and AZT

Two recent studies show that AZT treatment for HIV-positive pregnant women before and during delivery, and for their newborns, can reduce HIV transmission to the baby. A study in the USA called ACTG 076 showed that the chance of mother-to-baby HIV transmission was reduced by two-thirds when AZT was given during the last 20 weeks of pregnancy, intravenously during childbirth and to the newborn child.

However, there are many unanswered questions. The studies, in Europe and North America, involved only a small number of infants. The results may not apply to all HIV- positive women. AZT is toxic, and its long term effects on women and newborn infants are not known. Only one-third of infants born to women with HIV are HIV-infected themselves, therefore many uninfected babies could be exposed needlessly to AZT.

Although some pregnant women with HIV in Europe and North America are taking it, more follow-up is necessary. Following the Delta trial it seems likely that women who choose to take anti-viral treatment during pregnancy will be recommended combination therapy rather than AZT on its own.

Problems

There are several disadvantages to anti-viral drugs. It is now clear, for example, that the virus quickly becomes resistant to AZT. All these drugs are toxic and cause side effects such as nausea, anaemia and muscle wasting, and sometimes other serious illnesses. These side effects are more severe at higher doses and more likely to appear in people with advanced HIV infection. For people without symptoms there are fewer side effects but the long-term impact on their health has not been studied.

People taking anti-viral drugs need access to regular and expensive monitoring tests which require laboratory facilities and trained staff. For example, blood tests are needed to detect anaemia, as well as high enzyme levels in the blood which can lead to serious illnesses such as pancreatitis. Taking the drugs without medical supervision can do more harm than good.

How HIV works

After someone has been infected by HIV the virus begins to multiply rapidly in the body. The virus attaches itself to the surface of special white blood cells involved in fighting infections (CD4 cells). Then, after entering a CD4 cell, the virus bonds with the cell's DNA. DNA is the human genetic material which enables cells to reproduce. This means that when the cell tries to reproduce itself, it is forced to produce more virus instead of another human cell, and is also destroyed in the process.

At first, the person's inimune system is able to kill many of the CD4 cells which become infected with HIV. However, the virus is never totally destroyed. It continues to reproduce and eventually the immune system becomes unable to destroy the large numbers of HIV-infected cells. As the number of uninfected CD4 cells declines, the immune system becomes less able to fight illnesses.

WHO photo by T Farkas

Laboratory testing is only one part of the long process of developing new drugs.

Other types of anti-viral drugs are still very early stages of development. tudies are taking place to investigate rugs called 'protease inhibitors' such as aquinavir. Protease inhibitors aim to eactivate the special HIV enzyme which nables attachment to the white blood ells. Scientists hope that they will be less oxic than drugs such as AZT and ddI. rials are in preliminary phases and there s no evidence at present to suggest that ney prolong life or delay the development f HIV-related illnesses.

mmune system boosting

Another area of research focuses on trengthening or 'boosting' the immune ystems of people with HIV. It is hoped hat strengthening certain components of he immune system could protect HIV-positive individuals from developing llnesses. For example, treatments to ncrease the number of white blood cells could help the body to fight HIV for longer.

There is debate among scientists about the value of these treatments. ncreasing the number of white blood cells could also increase the number of these cells that are infected with HIV. The only arge trial, carried out with 'imuthiol' or DTC, found no clear evidence of benefit and even a possibility that it hastened development of HIV-related illnesses. Another drug called 'interleukin 2', already used for kidney cancer, is about to be tested for its effect on the number of CD4 cells. Experimental trials with drugs used for other illnesses are also under way.

The immune system may also be suppressed when someone is poorly nourished or under stress. Many people living with AIDS can feel healthier and stronger if they are able to change their lifestyle and diet and reduce stress. Alternative approaches to strengthening the immune system involve using Chinese medicine and acupuncture, herbal medicines and forms of relaxation. Some herbal medicines are being studied although no scientific research has yet been completed. Traditional and herbal remedies will be looked at in future issues of *AIDS Action*.

Affordable and effective?

The results of recent studies are encouraging. However, therapies are extremely costly and many have side effects. Even people in North America and Europe, who have access to these treatments, are deciding not to take them. Unless effective and low cost therapies can be developed, the prevention and treatment of opportunistic infections such as TB and diarrhoea continue to be the best strategies for most people with HIV. Appropriate care and 'positive living' can reduce stress and improve quality of life.

Keith Alcorn, National AIDS Manual, 52 Eurolink Centre, 49 Effra Road, London SW2 1BZ, UK. (See p12 for NAM publications.)

Developing new drugs

New treatments need to be tested for safety and effectiveness in several stages, before they can be licensed for commercial manufacture. The research process can take many years and involves:

- laboratory studies to assess the impact of the drug on the virus itself
- research on animals to study effects on health and the immune system
- small scale studies/trials with volunteers to test for side effects and impact on health and immune system
- large scale studies with many people for at least a year to prove safety and effectiveness.

Reports in the media about the discovery of a cure often raise false hopes because all the trial stages have not been completed. There is much debate about whether drugs should be made available before the final stage is completed, because the need for treatments is so great. Some drug companies have run lotteries to select trial participants, because so many people volunteer to take part.

Eat healthily, stay healthy

Good nutrition is essential for health. ***AIDS Action*** *looks at nutritional needs of people with HIV.*

It is extremely important for a person living with HIV to eat a nutritious diet. A well nourished person is less vulnerable to illness whether or not they have HIV infection. Both HIV and poor nutrition can damage the immune system.

It is important to have reserves of energy to combat infections such as TB which use up the body's energy, or diarrhoea and vomiting which result in loss of nutrients. Both emotional stress and opportunistic infections can reduce a person's appetite. Infections in the mouth and throat, such as thrush or open sores, can make eating difficult and painful.

Some studies have shown that HIV itself can cause severe weight loss. This can take the form of muscle wasting where muscle and other protein stores are used up, in addition to fat reserves. Healthy people with HIV infection are advised to eat as much as possible of a balanced diet. Some people like to take special vitamin and 'energy-rich' supplements. However, these are costly and are not necessary.

It is especially important for people with HIV to have enough proteins and micronutrients such as vitamin A and iron. Vitamin A plays a key role in keeping the immune system healthy. Studies show that children who lack vitamin A have more frequent diarrhoea and respiratory infections.

Nutritious and easy to eat

Some foods can be made more nutritious and easy to digest. Porridge can be made more energy-rich by adding nuts or oil, by replacing some of the water with fresh milk or coconut milk, or by adding mashed fish, dark green or orange fruits and vegetables or fruit juice.

Traditional weaning foods can be adapted for people who are sick or having difficulty in eating. Porridge can be made thinner, easier to swallow and more nutritious by 'fermenting' or 'malting'.

Fermentation turns some of the starch in the flour into acidic products. This sours the porridge, making it thinner with a higher concentration of nutrients, and also increases the absorption of some nutrients such as iron and zinc. Bacteria which cause diarrhoea are less likely to grow in soured than in ordinary porridge. One way to make soured porridge is to mix flour with water so the mixture is liquid, leave it to ferment overnight, and then cook as normal. The flour and water mixture becomes more sour the longer it is left. Cooked porridge can also be soured by adding a spoonful of previously fermented porridge.

Malting means allowing cereal grains to germinate (start sprouting) by soaking them in water for two days, spreading them out on sacks and covering them with a damp cloth. They are then left in the dark and kept damp for two to four days. After malting, the grains should be washed and dried before they are roasted, fermented, or pounded into flour. It is important not to use grains which have developed mould because this can become toxic.

Helping with difficulties

What is good for a healthy person is good for a sick person. However, people who are sick with HIV-related infections may need a diet that helps them to:

- increase their appetite and take in enough nutrients
- help the digestive system cope with and recover from diarrhoea
- recover weight and strength lost during illness.

During illness

It is important for the person to continue to eat as much as possible. The food should be easy to eat and easily absorbed.

Mouth sores: the person may prefer to eat food that does not need to be chewed, for example milk, porridge, soup, or mashed fruit or vegetables. It is important not to make the food too watery because this reduces the amount of nutrients. Cool food can be more soothing than hot food. Avoid using spicy and peppery foods.

The World Health Organisation Golden Rules for Safe Food Preparation

1. Choose foods processed for safety
While many foods, such as fruits and vegetables, are best in their natural state, others simply are not safe unless they have been processed. For example, always buy pasteurized as opposed to raw milk. Certain foods eaten raw, such as lettuce, need thorough washing.

2. Cook food thoroughly
Many raw foods, most notably poultry, meats and unpasteurized milk, are very often contaminated with disease-causing pathogens. Thorough cooking will kill the pathogens, but remember that the temperature of all parts of the food must reach at least 70°C. If cooked chicken is still raw near the bone, cook it again until it's done — all the way through. Frozen meat, fish, and poultry must be thoroughly thawed before cooking.

3. Eat cooked foods immediately
When cooked foods cool to room temperature, microbes begin to proliferate. The longer the wait, the greater the risk. To be on the safe side, eat cooked food just as soon as they come off the heat.

4. Store cooked foods carefully
If you must prepare foods in advance or want to keep leftovers, be sure to store them under either hot (near or above 60°C) or cool (near or below 10°C) conditions. This rule is of vital importance if you plan to store foods for more than four or five hours. Foods for infants should not be stored at all.

A common error, responsible for countless cases of foodborne disease, is putting too large a quantity of warm food in the refrigerator. In an overburdened refrigerator, cooked foods cannot cool to the core as quickly as they must. When the centre of the food remains warm (above 10°C) for too long, microbes thrive, quickly proliferating to disease-producing levels.

continued on the next page

or appetite: it is best for the person to small amounts more often than usual. e a variety of foods that the person s. If they feel nauseous, avoid strong elling foods and cooking smells that ger.

arrhoea: this damages the gut so fewer trients are absorbed. Damaged estines need easily digestible foods ch as porridge or soups. In some cases ty or oily foods can worsen diarrhoea cause the gut cannot absorb them. Milk n also cause poor absorption in a few ople. Damaged intestines are metimes intolerant to lactose, the sugar und in milk. If the diarrhoea persists the rson can consider excluding milk from eir diet to see whether the diarrhoea ssens. Other nutritious foods should be ken instead. Antibiotics can also worsen arrhoea.

During illness, especially diarrhoea nd vomiting, make sure the person drinks xtra fluids to prevent dehydration, such s thin porridge, coconut water, fruit ices, thin vegetable soups or yoghurt-ased drinks. Oral rehydration salts olution can be taken if available.

uick recovery

When an acute infection passes it is nportant for the sick person to have extra ood in order to repair the gut, rebuild uscles and replace the body's store of utrients that has been used up during e illness. This extra food is needed until e body has regained weight. The person hould try to eat one extra meal each day, nd it is good to have extra food at each eal.

taying well

When the person is feeling stronger, they hould try to continue eating well, ncluding foods that have not been eaten uring illness.

or women and children

ll pregnant women need extra nutrients, specially if they are anaemic (iron eficiency). It is important for all pregnant omen to have enough vitamin A through ating dark green leaves or orange fruits nd vegetables, and, if available, liver or gg yolk. A study in Malawi has indicated hat babies born to HIV-positive women ith vitamin A deficiency are three or four mes more likely to have HIV than those orn to HIV-positive women with normal evels of vitamin A. It is thought that this s because vitamin A is important for the mmune protection provided by the mother and prevents HIV from passing across the placenta from mother to child. This finding is being investigated further.

Breastmilk is the best form of nutrition for every infant, especially during diarrhoea. If the mother has decided not to breastfeed, for example due to severe HIV-related illnesses, ensure that the child is fed adequately using a cup and spoon (see AIDS Action 27). After an attack of illness give older children an extra meal until they are at least the same weight as before the illness.

Community coping

It is often difficult for people living with HIV and their carers to eat well. Illness in a family is often linked with poverty, because, for example, adults may be too sick to cultivate land or to earn income.

Food aid Some NGOs provide food aid to families. However, many people in poor communities are badly nourished or sick, not just those with HIV. Providing food only to people known to have HIV draws attention to them when they may prefer to keep their HIV status confidential. Some NGOs have chosen to provide food through schools and mother and child health or TB clinics. One NGO in Tanzania provides food to families where the household has an orphan or is headed by a child, elderly person or woman with no land. Decisions about who receives food are made by local committees.

Maintaining food production It is important to work with local people and agricultural programmes to avoid food shortages caused by a decline in farming. Providing technical support, such as training on crop diversification and livestock management, transport, storage and marketing, or providing credit can lessen food shortages and increase income. Some organisations work with legal associations to ensure land inheritance for widows and children who would otherwise lose their land on the death of a partner or parent.

Home care Home care and counselling should include information about nutrition. Some organisations are running courses for people with HIV and their carers about improving nutrition with locally available products.

---

continuation of "WHO Golden Rules..."

5. Reheat cooked foods thoroughly
This is your best protection against microbes that may have developed during storage (proper storage slows down microbial growth but does not kill the organisms). Once again, thorough reheating means that all parts of the food must reach at least 70 °C.

6. Avoid contact between raw foods and cooked foods
Safely cooked food can become contaminated through even the slightest contact with raw food. This cross-contamination can be direct, as when raw poultry meat comes into contact with cooked foods. It can also be more subtle. For example, don't prepare a raw chicken and then use the same unwashed cutting board and knife to carve the cooked bird. Doing so can reintroduce all the potential risks for microbial growth and subsequent illness prior to cooking.

7. Wash hands repeatedly
Wash hands thoroughly before you start preparing food and after every interruption — especially if you have been to the toilet. After preparing raw foods such as fish, meat, or poultry, wash again before you start handling other foods. And if you have an infection on your hand, be sure to bandage or cover it before preparing food. Remember, too, that household pets often harbour dangerous pathogens that can pass from your hand into food.

8. Keep all kitchen surfaces meticulously clean
Since foods are so easily be contaminated, any surface used for food preparation must be kept absolutely clean. Think of every food scrap, crumb or spot as a potential reservoir of germs. Cloths that come into contact with dishes and utensils should be changed every day and boiled before re-use. Separate cloths for cleaning the floors also require frequent washing.

9. Protect foods from insects, rodents and other animals
Animals frequently carry pathogenic microorganisms which cause foodborne disease. Storing foods in tightly sealed containers is your best protection.

10. Use clean water
Clean water is just as important for food preparation as for drinking. If you have any doubts about the water supply, boil the water before adding it to food or making ice for drinks. Be especially careful with any water used to prepare an infant's meal.

Sources: Semba R, 1994, 'Maternal vitamin A deficiency and mother-to-child transmission of HIV-1', The Lancet, vol. 343, no 8913, p1593-1597.
'Malnutrition and chronic diarrhoea - nutrition guidelines'(draft), 1995, City Health Department, Mutare, Zimbabwe.

AIDS: everyone's task

Organisations working in community health development have a key role in AIDS education. EPES, a community health group working in Chile, describes how they developed the game on page 7.

When we started talking about AIDS we realised that we did not have any teaching materials to share knowledge with people in a participative way. So in 1989 we developed a board game called Learning about AIDS: everyone's task. The game is based on local people's experiences and aims to:

- provide basic information on HIV/AIDS
- encourage discussion about ideas, beliefs and myths about AIDS
- give opportunities for open exchange of opinions and views about sexuality and AIDS
- promote awareness of how AIDS affects the community and the need for HIV prevention.

Everyone is affected by AIDS and has a role to play in fighting the epidemic. Every community is able to respond in a supportive, caring and effective way. But people need opportunities to discuss the issues and think about their attitudes and feelings.

The game uses two sets of cards: 72 'Everyone's task' cards with questions on HIV transmission and prevention; and 35 'Community' cards describing possible situations in the community where problems and issues about HIV and AIDS could arise (see examples). The issues are discussed in a booklet which accompanies the game. It is essential to have a skilled facilitator who is aware of the issues that arise when talking about HIV and sexual health.

People play the game in pairs using dice. Each player in turn moves their counter forward the number of squares on the board shown on the dice. If the counter lands on a square marked with 'Everyone's task' the person picks up a card and answers it. When a counter lands on a 'Community' card square the group discuss the issue. These cards do not have 'right' or 'wrong' answers.

The game was designed with a group of people involved in education or living with AIDS and is based on real life experiences. Each group who uses the game can change it for local use. For example, a group of students at the local university played the game during a special event. They made a large-scale version on a football pitch, built life-size models of the community buildings and made a giant dice. Groups in other countries could develop a new set of issues and questions for the players to consider.

The game can be a useful part of an HIV prevention strategy which includes three key elements: relevant information and education; access to services; changing social attitudes to enable every individual to develop their own sexuality healthily and safely. The game both provides information and challenges the players to think about all the issues in their community.

Sonia Covarrubias, EPES, Casilla 360-11, Nuñoa,Santiago, Chile.

Sample 'Community' cards:

Clinic: Free condoms are available at the clinic for HIV prevention. Should condoms be given out free? What do you think?

Pharmacy: The pharmacy on the corner sells condoms. In a role-play show how you would ask for a condom, with your partner playing the part of the pharmacist.

Home: Your husband is going away for a football match at the weekend. You are worried about AIDS and afraid that your husband will have an affair while he is away. How do you talk with him about this?

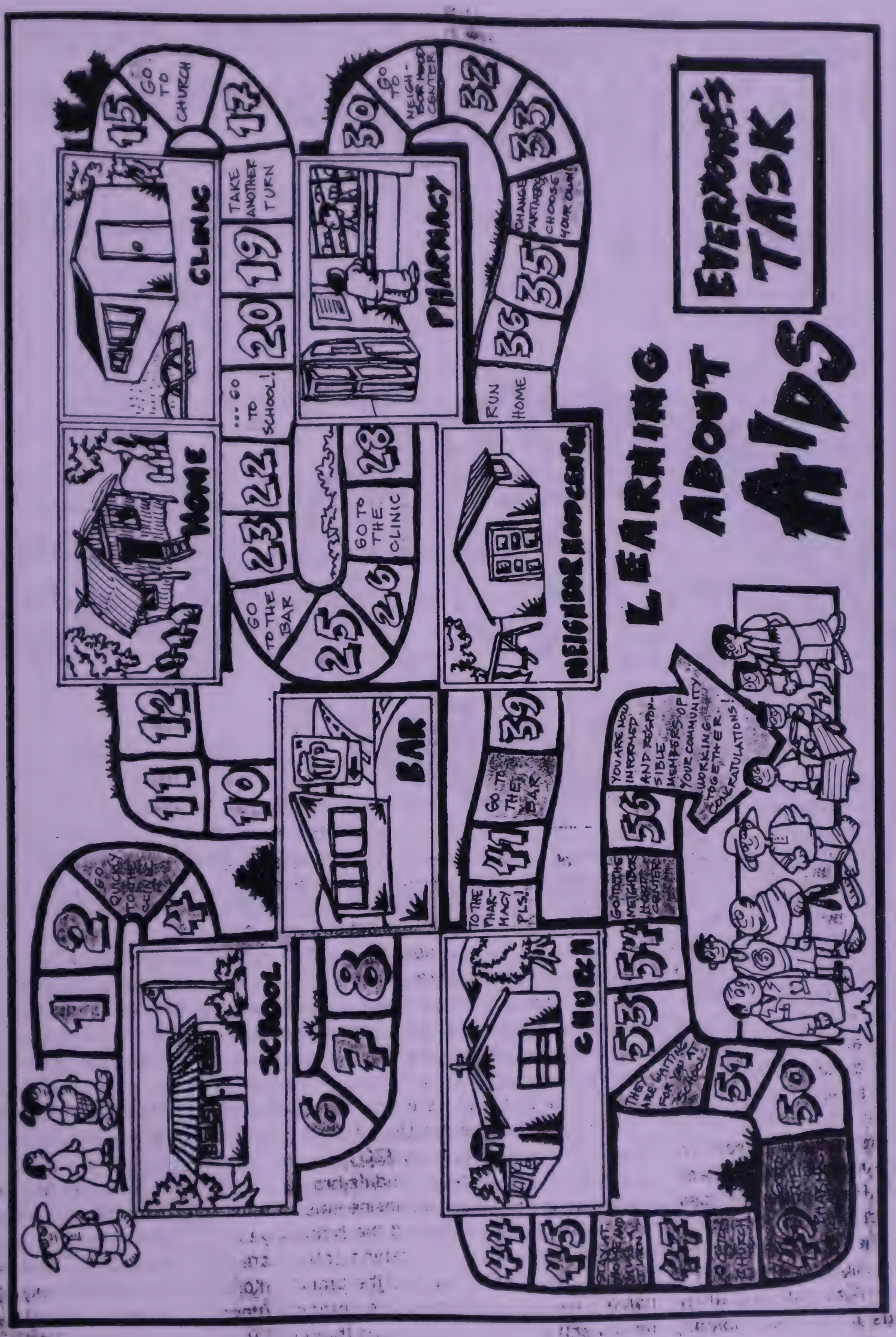
School: A teacher says 'If we teach children in school about sexuality and AIDS we will encourage them to be more sexually active.' What is your opinion?

Neighbourhood centre: In a community meeting a neighbour asks why there is no compulsory HIV testing. She is afraid and thinks that we should know who has HIV to be able to help them. What do you think about mass compulsory HIV testing?

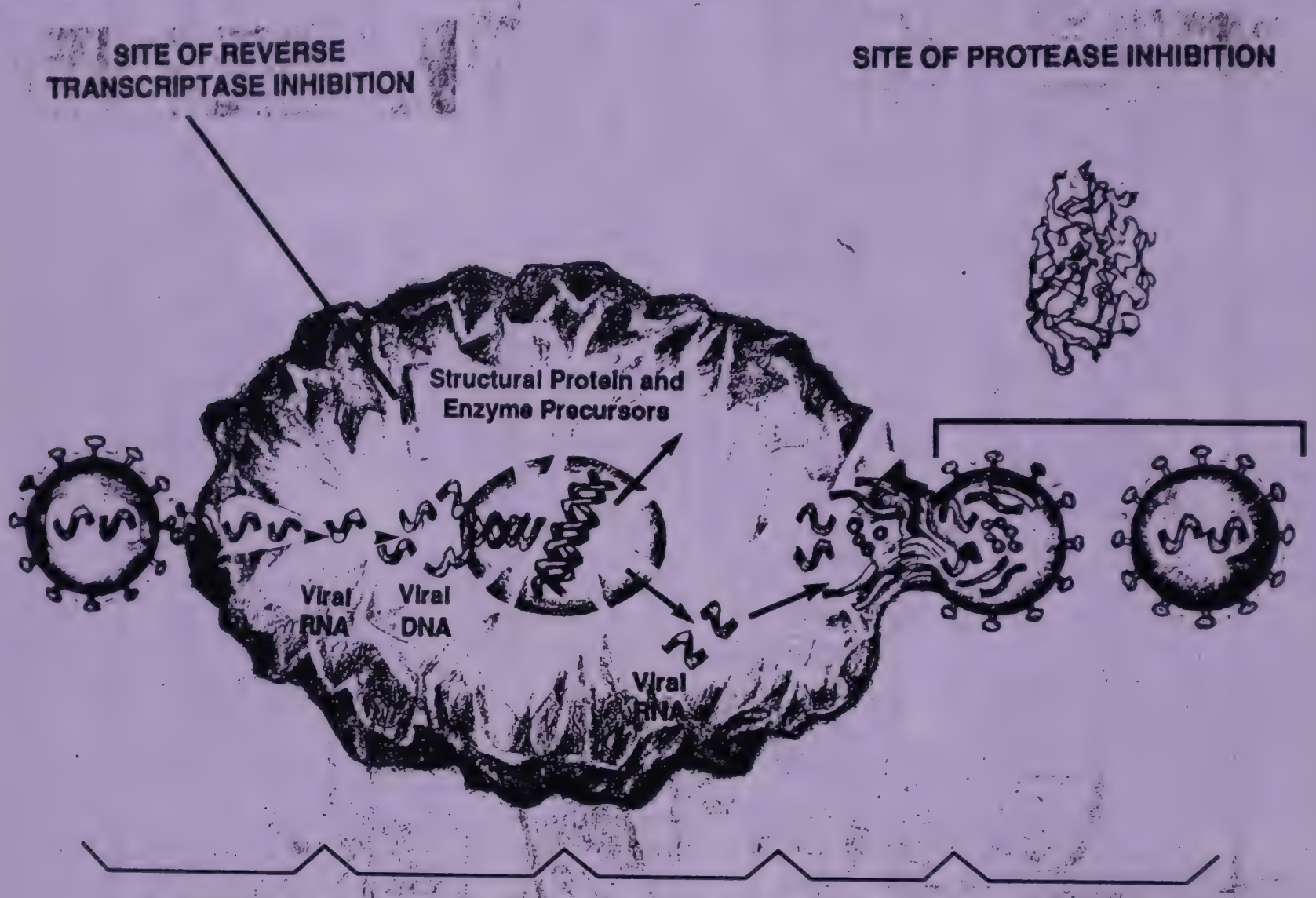
Bar: [illegible] is applying for a job as a [illegible] bar in town. They insist that [illegible] before getting the [illegible] have HIV tests

Sample 'Everyone's task' cards:

- What is AIDS?
- What is an 'immune system'?
- Are HIV symptoms the same in men and women?
- Name three ways in which someone can become infected with HIV.
- Name various ways of reducing the risk of HIV transmission.
- Does everyone with AIDS die because of this illness?
- Should someone with HIV continue in his or her job?
- True or false: married people do not get HIV.
- Can using drugs or alcohol contribute to risk of HIV transmission?
- Do birth control methods prevent HIV transmission?


LEARNING ABOUT AIDS
EVERYONE'S TASK
HOME
CLINIC
PHARMACY
NEIGHBOR HOOD CENTER
BAR
SCHOOL
CHURCH
GO TO CHURCH
TAKE ANOTHER TURN
... GO TO SCHOOL!
GO TO THE BAR
GO TO THE CLINIC
RUN HOME
GO TO NEIGH-BOR HOOD CENTER
CHANGE ARTNER'S CHOOSE YOUR OWN!
GO TO THE BAR
GO TO THE PHARMACY PLS!
YOU ARE NOW INFORMED AND RESPON-SIBLE MEMBERS OF YOUR COMMUNITY WORKING TOGETHER! CONGRATULATIONS!
THEY ARE WAITING FOR YOU AT SCHOOL!

Anti-HIV drugs: how do they work?



There are now two groups of drugs that have been approved for use in HIV infection. These drugs do not cure HIV infection. What they do is to inhibit the reproduction of HIV. There are two groups of anti-HIV drugs that do this: reverse transcriptase inhibitors and protease inhibitors.

For HIV to reproduce, it needs to have its genetic material "transcribed" in the host cell. Reverse transcriptase inhibitors affect this transcription process. The other group of drugs are called protease inhibitors. These affect another stage in HIV reproduction, when the virus needs to be "assembled." Protease inhibitors block this assembly process and therefore new HIV is not produced. All of this takes place within the CD4 or helper T cell, the host for HIV. The following illustration shows the sites where the drugs work.

Reverse transcriptase inhibitors that have been approved in the United States and Europe are zidovudine (ZDV, also known by its old name AZT and its brand name Retrovir); ddI or didanosine (also known as dideoxyinosine and the brand name Videx); ddC or zalcitabine (also known as dideoxycytidine and the brand name Hivid); d4T or stavudine (brand name Zerit) and 3TC or lamivudine (brand name Epivir). Nevirapine (brand name Viramune) is the latest of these drugs to be approved in the United States. Nevirapine is a non-nucleoside reverse transcriptase inhibitor (NNRTI) while the other drugs approved earlier are nucleoside analogues. The NNRTI have less severe side effects than the nucleoside analogues.

Protease inhibitors are newer drugs that have been approved over the last year. The approved protease inhibitors are: saquinavir (brand name Invirase); ritonavir (trade name Norvir) and indinavir (trade name Crixivan).

10.2.

HIV/AIDS and Essential Drugs: Issues of Access and Affordability

IV and essential drugs

With the increasing numbers of people infected, AIDS researchers and tivists are beginning to face the reality at to cure HIV infection may be an realistic goal. The retrovirus integrates elf into the host cells where it can remain ent for long periods of time, virtually detectable and out of range of any erapeutic intervention.

Several antiretrovial drugs — reverse anscriptase inhibitors and protease hibitors — have been developed at a pid pace over the last few years. These ugs work mainly by inhibiting the production of HIV buf they do not cure IV infection. While they are now utinely used in developed countries, eir high cost precludes their use in eveloping countries.

The oldest antiretroviral drug being sed is zidovudine (also known by its older ame AZT and by its brand name etrovir). In Malaysia, the government till subsidizes patients with HIV under a pecial budget allocation but the rospects of continuing this subsidy will ecline as the number of patients crease. The costs can be substantial if he patient has to shoulder the expenses. he cost of a year's treatment can run up 9240 ringgit (about US$3696).

Over 90 per cent of patients who evelop advanced HIV infection or AIDS ventually die from opportunistic nfections. All these infections are eatable, often with drugs that have been n the market for many years, but many f these drugs are also expensive. In the hilippines, for example, the daily cost of ral treatment with the antifungal etoconazole (200 mg) would cost P78, hich is about US$3, half a day's wages the nation's capital. Other drugs used for opportunistic infections are even more expensive, such as those used for tuberculosis and for pneumonias.

Impact of HIV/AIDS on health care services

From 1983, developing nations have faced strong pressure to reduce their public expenditure on health services and other social sector services. In many developing countries, the last decade saw the proportion of government expenditure on health fall as much as 50 per cent. The structural adjustment programmes (SAPs) of the World Bank (WB) and International Monetary Fund (IMF) further contributed to the worsening income distribution and inefficiency in resource allocation and use. The result has been drastic cutbacks in budgets for social programmes such as health, education, housing, etc. Impoverished developing countries have been advised by WB/IMF to privatise health and charge user fees in public sector health care services. Unfortunately, the AIDS pandemic has hit developing countries during this time of drastic cutbacks on health budgets and worsening income distribution of its peoples.

The costs of HIV/AIDS to the public sector in most developing countries in Asia and the Pacific consists of the direct costs of treatment and the indirect costs arising from loss of productivity and income. The direct costs of treatment include costs of drugs, length of hospitalization, and the number of hospitalizations required per year for each AIDS patient. Direct costs also include the cost of control and prevention measures.

Because a considerable portion of the health budget in most developing countries is spent on drugs, the trend now in these countries is for the private sector to increasingly take over drug supply. This is either a deliberate state policy, or because finance for the public sector is lacking. As a result, the costs of drugs have become prohibitive particularly for the vast majority of poor.

In these countries also, where the purchasing power of households has decreased in the 1990s, the effect or impact on the HIV infected individual is devastating. The decrease in purchasing power has contributed to an increase in demand on public health care services. With HIV/AIDS, the demand is exacerbated. SAPs, by increasing the price of imported drugs and in reducing public expenditures, has led in many countries to an aggravation of shortages of essential drugs in health facilities. The impact on AIDS patients has been devastating.

The problems are further compounded by a powerful pharmaceutical industry. For example, expensive branded drugs are favoured over generic substitutes of equal if not better quality. The recent Uruguay Round of the General Agreement on Trade and Tariff (GATT) has resulted in a globalization of patents for pharmaceuticals, which will put many important drugs beyond reach. Countries such as India have in the past been able to produce low-cost drugs because the treatment of HIV/AIDS related infections becomes a deterrent for the vast majority of poor who are infected with the virus and who cannot afford the costs. This situation also encourages the practice of self-medication which is far from rational, the use of traditional medicines and substandard but cheaper drugs which have not been tested for efficacy, quality and safety. In these countries, training on rational drug use is still insufficient,

information reaching the prescriber and consumers is far from satisfactory, drug management remains weak and drug promotional practices continue to give cause for concern. The inappropriate use of medicines, even if not HIV-related, can in the long term affect HIV as well. Consider, for example, self-medication with antibiotics for sexually transmitted diseases. Incomplete treatment means these diseases remain widespread, and actually increases vulnerability for HIV infection.

Conclusion

In the Asia Pacific region and other parts of the developing world where almost one billion people live below the poverty line and where the impact of the epidemic will be the hardest, a major portion of health care costs for the treatment of HIV/AIDS are being borne by the people themselves and not by the governments. Drug treatment of HIV/AIDS is very expensive. It is imperative that a strategy for containing costs must be found particularly in the pharmaceutical supply systems as this accounts for majority spending of the health budget.

One way to do this is for governments to formulate and implement an integrated national drug policy (NDP) based on the concept of essential drugs and their rational use. The objective of a NDP is to enable governments to maximise resources and ensure the appropriate use of drugs. Some of the major components of a NDP include:

i. Selection of a list of essential drugs to meet the health needs of the people;

ii. Use of generic drugs;

iii. Criteria of drug registration to be based on safety, efficacy, quality, health needs and costs;

iv. Centralised bulk purchase of drugs using international tenders;

v. Regulation, control and monitoring of: drug prices and drug promotion;

vi. Provision of objective information to prescribers;

vii. Local production of drugs;

viii. National legislation on patents to exclude pharmaceutical products from patent protection;

ix. Comprehensive drug legislation empowering the Minister of Health or his/her representative to formulate rules and regulations to effectively implement the various components of the NDP, which should be applicable to both the public and private pharmaceutical sectors in a country; and

x. Finally, governments must draw up a public health and drug policy specifically for HIV/AIDS. This is extremely urgent considering the rapid spread of the disease particularly in Asia. This policy should be made part of the National Health Policy of the country.

- Shila Rani Kaur
Consumers International
Regional Officer for
Asia and the Pacific

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ANNOUNCEMENT

Asian AIDS IEC Resource Center

The Population and Community Development Authority of Thailand (PDA) in collaboration with the Asian Regional Office of the AIDS Control and Prevention Project (AIDSCAP) has established an HIVAIDS Information, education and communication (IEC) resource collection for the Asian region. The resource collection is based at the PDA's headquarters in Bangkok, Thailand.

The objective of the collection is to promote sharing of experiences and effective approaches to IEC-based HIV interventions by increasing awareness on and availability of IEC materials produced in English and Asian languages. The materials collected will be reproduced and disseminated in response to request from organizations in the region. The IEC materials will be described in a printed catalog and electronic data base, both of which will be made widely available. Using these resources, materials can be identified using search criteria such as target group, message themes, organization, types of materials available, and language. PDA will have a computer system available which will allow visitors using the center to search for materials.

PDA and AIDSCAP are inviting organisations in Asia to take part in this initiative by incorporating their IEC materials in the collection. Expenses incurred in the reproduction and shipping of materials will be reimbursed. PDA is equipped with the resources to photocopy representative samples of posters, pamphlets, books, magazines, and stickers, as well as reproduce all types of audio-visual materials. All organisations which have contributed their materials will be provided with a copy of the collection catalogue and details on how to access or obtain these materials.

The Asian AIDS IEC Resource Center operates for the benefit of all those working to prevent the spread of HIV infection in Asia. For more information contact the Resource Center at:

8 Sukhumvit 12
Bangkok 10110 Thailand
Tel: 229-4611-28
Fax: 2294632
E-mail : IECPDA@mazart.inet.co.th

Durex global survey : sexual olympics?

HIV/AIDS discussions can become dull and routine. Durex, a condom manufacturer, recently made headlines with the release of the results of a global survey on sexual attitudes and practices, with subtle messages on safer sex. Conducted in 15 countries with 10,000 respondents of both sexes, the global survey provides some interesting figures for comparing different countries, including two in Asia: Hong Kong and Thailand. Note that the Durex report only states that they used "appropriate research methods for the survey: we do not know if the research methods (sampling; questionnaires; interview methods) were "scientific" enough. Nevertheless, we present some of the research findings as food for thought.

The age for first sex varies from a low of 16.2 years in the United States to a high of 18.9 years in Hong Kong. Thailand, with a figure of 17.3, is quite close to the global average of 17.6 years. Unfortunately, there was no break down for males and for females.

The survey asked respondents how often they currently have sex. The global average was 2.1 times per week or 109 times a year. The United States had the highest frequency with 135 per year. Hong Kong had a frequency of 80 and Thailand scored the lowest among the 15 countries, with 64.

There were significant differences in the motivations for sex. The United States came out as the most "selfish," with 61 percent rating their personal satisfaction as top priority. Only 23 percent of the Americans mentioned "satisfying my sexual partner" as a priority and 16 percent said "not having an unwanted child." None of the Americans mentioned "not catching or spreading HIV/AIDS" or "not catching or spreading sexually transmitted diseases" as a priority.

The Canadians seem to be the most considerate, with 51 percent mentioning satisfaction of their sexual partner as a priority. However, in terms of preventing HIV/AIDS and sexually transmitted disease, the Thais seem to be the most conscious, with about 51 percent mentioning these as priorities, followed by Brazilians with 36 percent thinking of the prevention of HIV/AIDS and STDs. It is interesting though that the concern is usually over HIV/AIDS rather than STDs. Only in Hong Kong do we find great concern over STDs rather than HIV/AIDS. There, 18 percent of respondents mentioned STD prevention as a concern while 8 percent mentioned HIV/AIDS prevention.

In terms of actual practices, the Thais seem to be the most conscious about safer sex, with 82 percent saying they always use a condom with a casual sex partner. The Thais are followed by the French (69 percent) and the Australians (59 percent). Countries where respondents used condoms most were Hong Kong (27 percent); Canada (25 percent) and Poland (20 percent).

The survey also asked respondents to rank nationalities that they thought would make the best lover. The French and Italians came out on top. Hong Kong ranked 11th; the Thais ranked 13th. (The Russians were 14th and the Poles, the 15th).

Related findings were those on "national self-confidence" measured by the ratings given by respondents to their own countries in terms of their being the best lovers. The most confident were the Brazilians, with 89 percent voting for themselves, followed by Italians (85 percent) and Americans (83 percent). The Thais were somewhat intermediate, with 56 percent voting for themselves. The least confident nations were Poland and Russia (50 percent); Mexico (46 percent); and Hong Kong (31 percent).

Durex just could not resist the temptation. They decided to come up with a composite score looking at quality of sex (whether or not partner satisfaction is important); safer sex; and quantity of sex to come up with rankings on "which nationality really makes a great lover." The verdict? The French came out first. The British and the Americans tied for second. The Thais came out 12th and poor Hong Kong came in last.

Asian reactions to the survey? We were only able to monitor Filipino newspapers which, as usual, whined and complained... mainly because Filipinos – who think Filipinos are the best lovers in the world – were not included in the survey. Next round, Durex?

Source : Durex Global Survey 1996.

LETTER

Feedback on TB issue of *AIDS Action*

Congratulations on your Issue 30 on HIV and TB!

It has so far the most informative and practical communication materials I have read regarding HIV/AIDS and TB. I particularly commend your slant towards community based efforts, the sensitivity to gender issues and to the care for care-givers. Noteworthy as well are the discussions on the current issues ranging on the integration of programs and actions on TB and HIV/AIDS prevention and control.

We have requested all our UNICEF field offices in the East Asia and Pacific Region to subscribe to ***AIDS Action***, Asia Pacific edition.

Continue the excellent work that you are doing. All the best and more power!

Very sincerely,

Jaime Z Galvez Tan
Regional Adviser - Health and Nutrition
UNICEF EARPRO, Bangkok 10200 Thailand

RESOURCES

Nutrition for Developing Countries is a practical guide for nutrition workers working in the community and gives basic facts on nutrients and food. *Available for £3.95 from TALC, PO Box 49, St. Albans, AL1 4AX, Herts, UK.*

What has AIDS to do with agriculture? is a booklet for agriculture workers and planners in HIV affected areas. *For price and availability, write to Publications Division, FAO, Viale delle Terme di Caracella, 00100, Rome, Italy.*

WHO model prescribing information: drugs used in sexually transmitted diseases and HIV infection is addressed to clinicians, particularly those in developing countries, as a guide in the selection and prescribing of drugs, in line with the latest knowledge on efficacy, safety, and costs. *Available in English; French and Spanish in preparation. Sw fr 17.50 for developing countries. Write to : WHO Distribution and Sales, 1211 Geneva27, Switzerland.*

Newsletters

AIDS Treatment Update is a monthly newsletter providing information about new clinical trials and treatments that are available mostly in Europe and North America, but can be useful for health workers and researchers in developing countries. *Available for £40 per year from NAM, Unit 52, The Eurolink Centre, 49 Effra Road, London SW2 1BZ, UK. NAM also produce a twice-yearly A-Z of treatments and opportunistic infections, the HIV & AIDS Treatments Directory.*

AIDS Treatment News is published 24 times a year. It provides information on experimental and standard treatments for HIV disease, mostly aimed at North America and Europe. *Available for US$120 per year or US$60 for six months from AIDS Treatment News, P O Box 411256, San Francisco, CA 94141, USA .*

Pacific Islands Nutrition is a regional newsletter for nutritionists, dieticians, and nutrition educators in the Pacific. *Contact South Pacific Commission, B.P. 05. 98848, Noumea Cedex (New Caledonia).*

There are many groups set up by people living with HIV and AIDS providing support on treatment issues and care, including nutrition. *For more information about local groups contact* ***Global Network of People Living with HIV and AIDS (GNP+), 62B Race Course Road Singapore 218 568, The Netherlands or International Community of Women living with HIV & AIDS, PO Box 2338, London W8 4ZG, UK.***

action

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10

MATERIAL ON HIV/AIDS

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ASIA-PACIFIC EDITION

MAKING PROGRESS

All of us involved in HIV prevention and sexual health promotion, or in caring for people with AIDS, want to know how useful our work is. This issue of *AIDS Action* looks at simple ways to collect information about our work and its effect on people, help plan future activities and adapt to changing situations.

It is also important for projects to be planned and monitored well so that senior managers or funders understand how the aims of the project are being achieved. This makes it easier for staff to participate in external evaluations and develop proposals for funding.

Monitoring and Evaluation

The words planning, monitoring and evaluation can sound technical and off-putting. Often projects are evaluated by outsiders in order to justify continued funding or political support and this can make an evaluation very threatening.

However, monitoring and evaluating do not need to be difficult. If monitoring is built into daily activities, and if evaluation is carried out regularly with the involvement of the target audience, projects become more rewarding and effective.

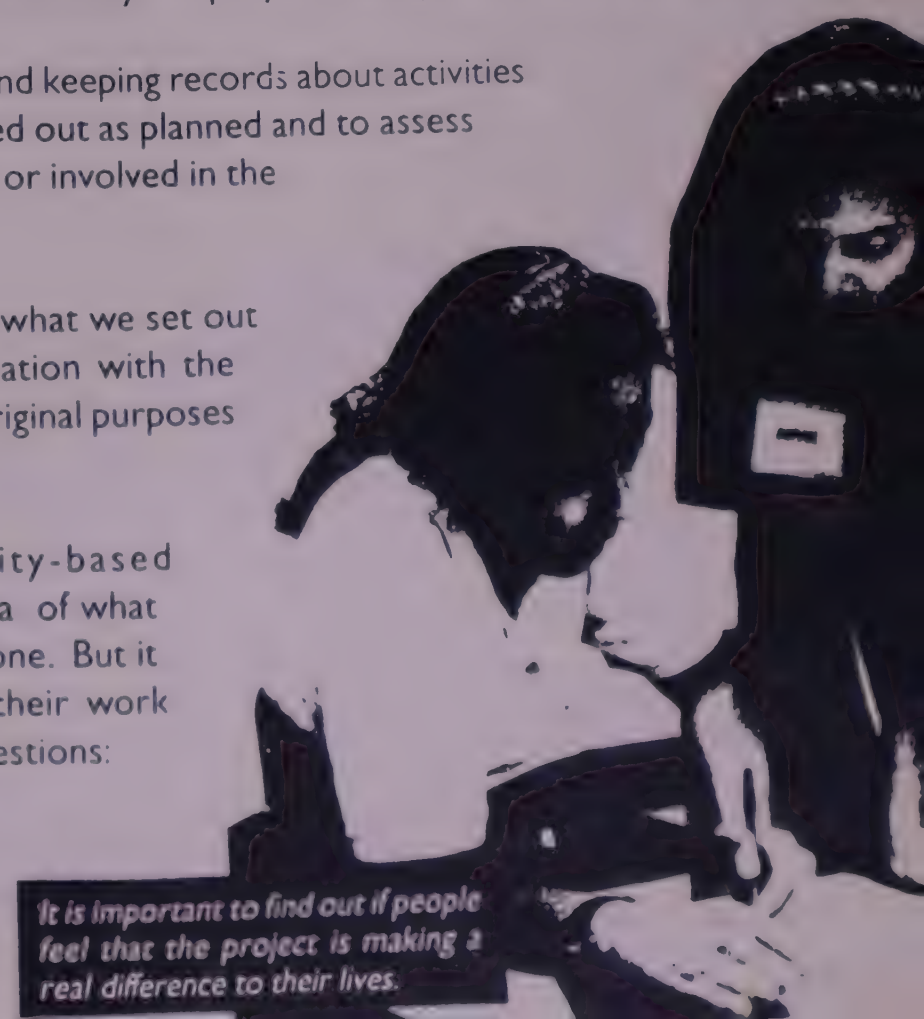
Both monitoring and evaluation are necessary for project management and planning.

Monitoring means collecting information and keeping records about activities to check whether the work is being carried out as planned and to assess reactions of people receiving the services or involved in the project.

Evaluation means asking "Did we achieve what we set out to do?" and comparing the present situation with the past in order to find out to what extent original purposes have been achieved.

People working in community-based organisations often have a very good idea of what they are doing and how well it is being done. But it is very important for them to review their work regularly in order to answer two key questions:

- are project activities achieving what they had set out to do?
- Is the project making a real and positive difference to people's lives?



It is important to find out if people feel that the project is making a real difference to their lives.

Participation means consulting everyone who is affected by the work – staff, clients and the wider community – in the process of deciding what the project aims to do, how it is done and how its effect can be measured.

Most projects aim to improve a particular situation for a particular group or community. It is essential to involve people in identifying their concerns and problems, deciding which of these concerns are more important and possible to do, and what activities can best achieve these.

Participatory approaches are only possible when senior managers and decision-makers are willing to accept the opinions of the people affected at community level. However, it is impossible to involve everybody all the time.

Involving PEOPLE

Community participation is essential, but with whom and how?

Asking the right questions

It is useful to think about the following points to help decide who should be involved at what stage:

- What do you need to know and whose views and experiences are neccesary when planning your project and making it more effective? The more directly affected a person is, the more important their opinion. It is neccesary to involve those who often have less influence, such as people who are sick, young women or men, or those who are discriminated against by their community, such as injecting drug users or sex workers.
- Whose active support is essential for the success of the project, such as funders, managers, or leaders in the community? Try to include them in the process as much as possible.
- Who is likely to feel threatened by the possibility of change? Think about how you can gain their supp challenge their opposition if neccesary.
- Who takes decisions about the activites and who expected to act on the decisions? They need to be in especially in planning new activities that will need resources or training to implement.

All of us!

Communities are made up of different people with different concerns and priorities. People may see them as belonging to several different groups – defined by family, religion, workplace or a example.

Within any community, groups of people are discrimi against. Women often have status and power in deci making. In considering project's impact on women their role, changes in the follo areas may be useful to record:

- numbers of women staff an volunteers on the project
- roles of women and men in decision-making and skilled in project and community activities
- numbers of women who are literate, and who rece primary and secondary education compared to me
- roles of women and girls at home and in the commu – for example, often it is women and girls who care the sick people and children
- possibilities for employment for women and men lo
- women's and men's views on ability to negotiate sa sexual behavior in relationships
- level of reported and unreported domestic violence
- legal status of women, for exam in terms of inheritance and divo
- numbers of unmarried and mar women with access to sexual reproductive health informat and services
- women's views on the acceptabi of attending sexual health servi
- women's income levels and ac to earning potential, such as l rights or credit facilities.

It is useful to talk with women to ensure activities respond to their needs.

Project Plans

he diagram below shows the ent stages in a project's life, using an nary example of where staff at a center decide to develop a new HIV/ project with the local community.

Planning steps

hat do you want to achieve?
the overall purpose or aim of the project.

ind out what the situation is. Using ine surveys, needs assessment and ity setting excercises. Issues to survey y project include: HIV/STDs, factors easing risk such as male or female ation and poverty; condom availabilty; sexual activity and risk.

ow are you going to achieve the aim? These ometimes called **objectives** and refer to d strategies that can be measured over

What specific activities will achieve these ctives? Each activity needs to have a time e, a budget (including volunteer costs) and time allocated.

What results do you want to see from these ites? These are sometimes referred to as **omes** and must aim to fulfill your objectives. can be numerical targets (e.g. number of ple to be trained in six months).

How will you measure or *monitor* how far ities are achieving objectives? You need to ose markers or **indicators** which will show changes that occur. These suggest, but do prove, how far an objective has been eved.

What tools will you use to collect this rmation? Staff and community volunteers d to develop simple methods to collect rmation about activities and chosen cators (see pages 4 and 5).

How will you use this information for ning? Regular review of information will you see whether activities are going as ned and within budget. You may decide to the activity, change it, or start again. **casional in-depth evaluations** are also ded, followed by review of aims, objectives activities. The planning process then starts n.

Project Staff

1a. The new project aims to:
- improve sexual health among potentially vulnerable groups
- strengthen their coping strategies for reducing the spread of STD/HIV

2a. Staff prepare a baseline survey looking at :
- clinic STD figures
- STDs treated by traditional healers, private doctors and pharmacists
- deaths from HIV/AIDS, where known
- clinic attenders' assessment of service
- condom availability

3a. Staff decide that the project can achieve its aims by :
- improving STD care for women
- providing sexual and reproductive health education in clinic
- promoting and providing condoms

4a. The clinic staff plan to :
- train staff on HIV/AIDS/STDs
- provide STD education and treatment for women and men
- improve links with hospital e.g. training , drug supply and laboratory tests

5a. In the clinic, activities will result in :
- better STD diagnosis and treatment
- increased client knowledge about HIV/STDs and satisfaction with services
- increased contact tracing

6a. Clinic indicators could include:
- numbers of women seeking STD treatment
- numbers of women with STDs at ante-natal clinic
- numbers of condoms distributed
- reported client satisfaction and reduced stigma

7a. Tools include :
- clinic records
- medical supervisor checklist of counselling and diagnostic skills
- focus group discussions with clinic attenders every six months

8a. At regular project meetings, staff look at records, discuss any difficulties and review progress and possible improvements.

An evaluation includes surveys, interviews and record analysis for comparison with the baseline survey. The results are discussed internally and, with advisory group, written up for funders and national managers.

Community Links

2b. Staff set up meetings with groups including clinic attenders, women, religious leaders, teachers, traditional midwives, healers and young people, to discuss current situation and prioritise key concerns. An advisory group of representatives is selected to meet regularly with project staff at every stage, and co-ordinate community activities.

3b. With staff support, the advisory group decide on additional objectives, e.g.
- improve economic situation, especially of women
- encourage better communication, especially between young men and women

4b. The advisory group plan to:
- select and train community educators
- improve condom access via shops, pharmacies and community educators
- have community discussions about STDs and sexual relationships
- set-up income generation schemes

5b. In the community, results include:
- improved communication between men and women about sexual matters
- increased use of condoms
- increased actions to reduce poverty

6b. Community indicators could include:
- reported domestic violence/arguments
- condom sales in bars
- establishments of women's credit schemes
- more reports of sexual responsibility and willingness to use condoms

7b. Tools include:
- community questionnaire to ask about condom use, STDs, etc.
- observation of condoms displayed in pharmacies, shops and bars
- focus group discussions and community meetings

8b. Advisory group attends project meetings and discuss any issues with community.

Results are fed back to community meetings where the activities are assessed and the excercise of setting priorities is repeated.

Collecting Informatio

AIDS Action looks at some simple methods that community projects can use to monitor their work.

Most organisations are already collecting information about their activities – and often collecting more information than can be used! The important points to remember are:

- collect information systematically - record sheets are not useful if they are not filled in regularly
- be selective – only collect information that refers specifically to the ways you have decided to measure whether the activity is going as planned
- make sure that the recording system is easy to use and that the person using it understands and is committed to the process
- make sure that the information is collected by the person most involved in the activity. For example, supervisors who visit village health clinics are in the best position to do regular checks on drug supplies. Young peer educators are often the best people to fill in questionnaires with participants in a peer education session.

Finding out about feelings

Monitoring and evaluation can be especially difficult for projects working on sensitive issues such as sexuality and relationships, or challenging views about how men and women behave. It is hard to explore changes in people's sexual behavior, values, or attitudes. People may not want to share personal and sensitive information or may not feel able to say what they really think or do.

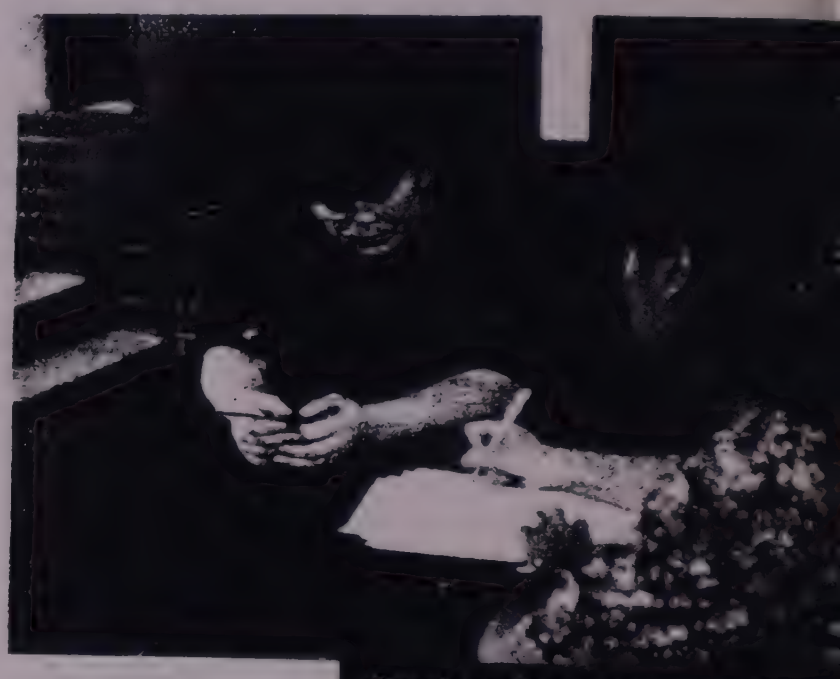
However, changes in public behaviour may be influenced by the same factors that affect private behaviour, and these are easier to observe. For example, activities aiming to increase young women's confidence in negotiating sexual relationships can be monitored by recording whether young women speak out more in meetings, and by asking them what they feel about their confidence levels.

What to Collect

Information that can be measured in numbers is often called quantitative. This means asking questions about when, who, which, how much or how often. Information about people's feelings or attitudes that cannot be measured in numbers is often called qualitative. Both of these methods are neded to be able to explore reasons for both expected and unexpected results and to examine some of the possible causes.

There are a variety of simple tools for collecting information:

- **records**, for example, of purchase and distribution of supplies, number of peer educators trained or community meetings held
- **questionnaires or surveys**, used to gather a broad range of answers to specific questions
- **diaries**, kept by participants i activity
- **group discussions** of case stud events, such as clinic staff ana why a child was not referre hospital in time
- **observing the community**, loo at events or people's behav and recording these observat



Simple and accurate record-keepi can be part of everyday work.

- **focus group discussions** wher people with specialist knowled or common interests discus specific topic in depth
- **interviews** with groups or individ to collect views on a partic issue, such as whether people v HIV feel that their quality of car improved following a trainin programme for their carers.

After collecting information it important to check your conclusions v the people involved, before planning furt activities.

A monitoring system can cost mo and must be included in the budget. example, training and supervising, print forms and staff time all cost mo Community and volunteers also have t own costs in time and energy.

Focus group discussions

A focus group discussion (FGD) involves talking about a ular topic in detail with a small group of people who share mon experience or area of interest, and are often of the sex and similar age. Holding a series of FGDs on the same or activity at different stages of a project can show how ghts, feelings and reported practices are changing.

Once a topic for discussion has been decided and the tives for the group set, a question guide should be drawn project staff. The questions need to be general and open- d to let people talk about their views and concerns.

For example, a question guide for an FGD which aims to out the needs of women carers might include:

One or two introductory questions to help people feel at and start a general discussion on the topic, such as: *When eone is sick in your family, who usually takes care of them? at are the advantages? What are the difficulties?*

Two to four general questions to encourage people to talk ut the main issues in their own words. For example, asking t they did yesterday to help the sick person in the family checking details, such as what tasks they did at different s of the day.

More detailed questions to find out responses to particular s or suggestions, such as : *How do you feel about taking e of someone who is sick at home? What is the most difficult g about taking care of someone with AIDS? Where can you or help when it is hard to care for someone alone?* These stions should pick up key issues raised earlier. It is sometimes

useful to have prepared a picture or a written list of questions to hand out.

Finally it is important to ask a general question such as : *Are there any other comments that you would like to make about taking care of someone who is sick at home?*

A facilitator leads the FGD, encourages people to talk freely and ensures that the conversation does not stray too far from the question guide. Another person records the key points of the conversation.

Ideally, a group should be between 6 and 12 people to allow everyone to participate. A discussion should not normally last more than an hour and a half. It is important to check that everyone agrees with what is being recorded and hears or sees the final report.

Questionnaires ???

A questionnaire or survey can be ul for collecting information from a er number of people. Everyone is ed the same questions so that the lts can be analysed and compared.

Designing the questionnaire

Decide what you want to find out from whom, and think about what stions are needed to obtain this rmation. Closed questions are those only need a "yes" or "no" answer or umber, for example: *Have you eived any AIDS education at school?* not to use questions which lead to rticular answer, such as *Do you agree the home care programme should you every month?* Open-ended stions require the respondent to give nger answer in their own words. For example: *What have you learned at school about HIV and AIDS?* It is useful to include some open-ended questions to gather opinions that you may not have expected.

Keep questions brief and use simple language. A question is easiest to understand when it addresses only one idea. Use exact words which cannot be misunderstood to obtain precise answers, such as: *How many times in the last week?* It is useful to collect only information which can be remembered accurately. For example, instead of *How many times did you feel sick last year?* ask *How many times have you been to the clinic in the past four weeks?*

Use words which are non-judgemental, such as *person with HIV* rather than *AIDS victim*, or *more than one sexual partner* rather than *promiscuous.*

Most importantly, keep the questionnaire short by avoiding unnecesary questions. If doing the questionnaire takes longer than 15 minutes, then people may become restless.

Preparation

The questionnaire should be checked (or pre-tested) with a small group of people who are similar to those who will be interviewed. This ensures that the questions are easy to understand, that people are willing to answer them and that the interviewers know how to fill it in correctly. The pre-test will also show whether the information collected is relevant and can be easily analysed.

Designing Appropriate Evaluations for HIV Prevention Interventions:

A Case for Behavioral Surveillance

"Did it work?" is the most common and critical question asked by organisations engaging in or funding HIV prevention interventions. It may seem simple enough, but embedded within the question is usually a host of other questions: *Did it work compared to nothing at all? Did it work compared to another intervention using another approach? Did it work to change behaviour? Did it work to reduce HIV prevention? Did it work to sustain the organisation over time?*

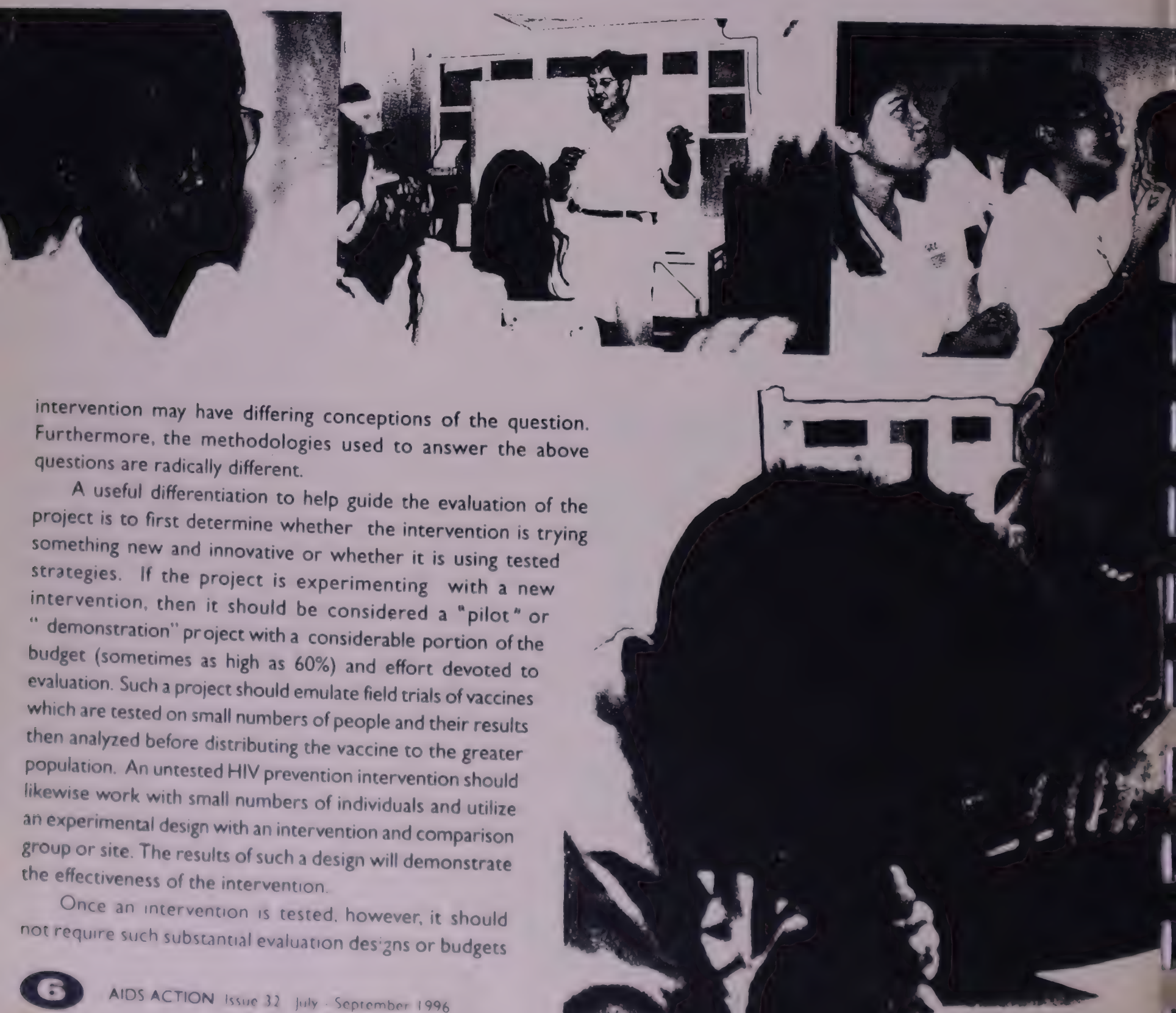
These multiple meanings of "what works?" are what frequently lead to misunderstandings about the effectiveness or success of a particular project since two individuals evaluating a project intervention may have differing conceptions of the question. Furthermore, the methodologies used to answer the above questions are radically different.

A useful differentiation to help guide the evaluation of the project is to first determine whether the intervention is trying something new and innovative or whether it is using tested strategies. If the project is experimenting with a new intervention, then it should be considered a "pilot" or "demonstration" project with a considerable portion of the budget (sometimes as high as 60%) and effort devoted to evaluation. Such a project should emulate field trials of vaccines which are tested on small numbers of people and their results then analyzed before distributing the vaccine to the greater population. An untested HIV prevention intervention should likewise work with small numbers of individuals and utilize an experimental design with an intervention and comparison group or site. The results of such a design will demonstrate the effectiveness of the intervention.

Once an intervention is tested, however, it should not require such substantial evaluation designs or budgets as noted above, but rather devote funds and effort to servi many people as possible to reduce disease prevalence. This not mean that such a service-oriented project should no evaluated, but rather that the evaluation should focus on diffe aspects of project implementation.

The table (at right) highlights the differences between p and service-oriented projects.

The AIDS prevention and Control Project (AIDSCAP Family Health International, a worldwide AIDS prevention pro for developing countries which is funded by the US Agency International Development, has been working on evalua



	Project Type	
	PILOT/DEMONSTRATION	SERVICE
AL	*Test the Strategy*	*Implement a Tested Strategy*
TING	*One Controlled Intervention*	*Overlapping Interventions*
PLE CHED	*Few*	*Many*
DGETS	*High Evaluation Budgets*	*Low Evaluation Budgets*
NAGEMENT	*Low management burdens*	*High management burdens*
CUS	*Concentration on measurement rigor*	*Concentration on service*
ING	*Depends on Study*	*Fast as possible to reduce disease*

tegies for HIV prevention projects for the past five years. ifically, AIDSCAP has been focusing on some alternatives to itional knowledge, attitude and behavior (KAB) surveys which been conducted by agencies for decades – from family planning IV – to determine the effects of their projects.

Evidence and experience from decades of KAB surveys ests that they have perhaps not been useful as originally eived. The reasons for this are varied. First, well-executed surveys require social scientific expertise which many ementing agencies do not possess. Furthermore, it is often alistic to attempt to build this expertise into an agency whose ion is essentially intervention-based, not research. Several ews of KAB surveys have pointed out that the sampling designs, stionnaires and analysis of a fair amount of KAB surveys have lacking in methodologic rigor.

Finally, it is not uncommon for several agencies e working in the same geographic area with the same ulations but providing different complimentary services. If each cy is required by their funding agency to conduct a KAB ey (which is often the case), this can lead to a plethora of low-quality data with little utility to anyone.

AIDSCAP has been increasingly implementing large-scale behavioral surveillance survey (BSS) projects to take the place of burdensome, unmanageable KAB surveys. Similar to KAB surveys, behavioral surveillance surveys are quantitative surveys based on a structured questionnaire. Unlike a KAB survey, however, the BSS is meant to serve as the evaluation instrument which provides indicators for a group of agencies who are working together in a specific geographic area with several target populations.

An organisation which implements a BSS project is usually a university or research firm with expertise in quantitative data collection. This organisation works closely with intervention agencies both in the data collection phase as well as in the analysis phase.

Examples of BSS include Bangkok, Thailand where AIDSCAP

Did it work compared to nothing at all?
Did it work compared to another intervention using another approach?
Did it work to change behaviour?
Did it work to reduce HIV prevention?
Did it work to sustain the organisation over time?

implemented a three-year, five-wave behavioral surveillance project with OPTA, a research firm, to provide information on sexual risk behaviors for over 10 agencies working with the Bangkok Metropolitan Administration in the Bangkok Fights AIDS Project. In the State of Tamil Nadu, India, AIDSCAP is assisting the AIDS Prevention and Control Project (APAC) of Voluntary Health Services in implementing a behavioral surveillance project of eight population groups across the state. The BSS there will provide yearly behavioral indicators for the project over five years. Similar BSS projects are in development with AIDSCAP assistance in Indonesia, Cambodia, and Senegal.

Behavioral surveillance can reduce much of the management burden of conducting evaluations of projects by consolidating the evaluation of multiple agencies and strategies within the high-quality project. It can likewise serve as an effective policy tool to inform government leaders and policy-makers on high-risk behaviors of key population groups.

EVALUATING Wildfire

Wildfire – a group activity which explores the emotional issues related to HIV/AIDS – was featured in the April-June 1995 issue of **AIDS Action** in the article "Understanding HIV" (page 7).

In the Philippines, Wildfire has been used by both non-government organizations and the Department of Health as a component in workshops on HIV/AIDS. Wildfire is not used on its own, but rather, it is part of a workshop package and complements the other activities conducted during the workshop.

To evaluate the effectiveness of Wildfire, a focus group discussion was conducted among Wildfire facilitators, who by now had gained a wealth of experience in using this learning activity. The facilitators were asked to share their experiences and give recommendations on how Wildfire could be improved.

Another FGD was conducted among nursing students who had just gone through a session of Wildfire in one of Health Action Information Network's workshops. The FGD among participants was intended to elicit feedback, and at the same time validate the inputs of the Wildfire facilitators.

Facilitators share their insights

The FGD among facilitators of Wildfire focused on questions regarding the effectiveness of Wildfire, factors which affect effectiveness, and recommendations on how the activity can be improved.

The FGD yielded valuable information which could be used by other facilitators to improve the conduct of the group activity. Highlights of the FGD are discussed below.

Factors that affect effectiveness

- **Capability of the facilitator.** The credibility as well as the skill of the facilitator is very important. Flexibility on the part of the facilitator would also contribute to an effective Wildfire session.

- **Composition of the workshop group.** Facilitators noted that a homogeneous group – one where the participants have similar characteristics – was often more effective than a heterogeneous group.

- **What comes before Wildfire.** Wildfire is part of a training package, and its placement within the workshop is crucial. Workshop participants would usually go through a discussion of basic HIV/AIDS before undergoing Wildfire. This way, they have a better understanding of the exercise. Wildfire also allows the workshop facilitators to check if the participants understood what had been discussed in the basic HIV/AIDS course.

- **What comes after.** Discussions or exercises in risk reduction measures are usually very effective after participants have undergone Wildfire. Having realized their potential vulnerability to HIV infection, they are usually more receptive to ideas and suggestions on how to reduce risk of infection.

The success of Wildfire as a learning activity rests heavily on the facilitator. The following are recommendations to improve the skill of the facilitator:

- **Experience Wildfire as a participant first.** Before a person facilitates a Wildfire session, experiencing Wildfire first as a participant would be of help. This way, the facilitator will be able to empathize better with participants of Wildfire sessions he or she will facilitate in the future.

- **Be familiar with the guide questions.** While beginners may need a checklist to make sure that the discussion flows through the correct process, it is better if the facilitators do not need to refer to the training manual while handling Wildfire. A short checklist of key words may be used instead.

- **Practice is essential for improvement.** The facilitators noted that it usually takes three sessions of facilitating Wildfire before the facilitator becomes fully comfortable and confident about what he or she is doing.

Basic Components of Wildfire

While the facilitators acknowledged that there is room for flexibility in the conduct of Wildfire, there are essential components which should not be left out, otherwise the activity's effectiveness may be lessened. These components (in chronological order) are:

- Introduction/instructions
- "Sexual transmission" (shaking of hands among participants)
- Prevention
- Realization of exposure
- Counseling/testing
- Living with HIV
- De-briefing

Feedback from Workshop Participants

The focus group discussion among nursing students who just participated in Wildfire centered on how they felt ng the Wildfire session, the messages conveyed by the up exercise, and their perceptions regarding the ctiveness of Wildfire.

For the workshop participants, there were many sages conveyed by Wildfire, among them the importance revention – otherwise the disease can indeed spread wildfire.

The workshop ticipants were ost unanimous in ng that Wildfire is ective. Wildfire s an opportunity explore the chosocial and otional aspects of V/AIDS at a sonal level. They t that the rkshop's vicarious erience of HIV at ersonal level made asier to understand complexities of ng with HIV and S.

Others cited the eraction among rkshop participants very strong point Wildfire. Listening the different spectives raised by ow workshop ticipants was in lf a major learning erience.

Some participants felt carried away by the strong otions aroused by Wildfire. It is in instances such as these the skill of the facilitator becomes even more crucial. o, de-briefing is a step which should not be missed.

With regard to ways to improve the conduct of dfire, some participants felt that there should have been eper "mental conditioning" or a more detailed briefing.

Some participants, however, perceived Wildfire as an "unnatural" situation, others felt that they were bound by the rules of the exercise to behave in a certain way. Understandably, some participants experienced negative feelings during the group exercise, particularly those who had been "exposed " to the virus. For example, one participant would not have had multiple partners in real life, thus risk of exposure would be lessened. The participant felt bad because she became "exposed" to the virus in the course of the group exercise, which she felt was unfair because she would have behaved differently in real life.

It is during situations such as these that the skill of the facilitator in handling emotional issues becomes very crucial. By processing negative feelings such as these, the facilitator can help the participants turn negative emotions into more affirmative learning experiences.

AIDS Action *would like to acknowledge the participation of the following Wildfire facilitators: Dyeri Andamo, Gladys Cortez, Joel de Mesa, Ted Nierras and Bernard Tomas.*

The FGD among Wildfire participants had representatives from the following academic institutions: Aquinas University, Bicol University, Ago Medical and Educational Center and Immaculate Conception College, all located in Albay, Philippines.

One World, One Hope: The Vancouver Conference

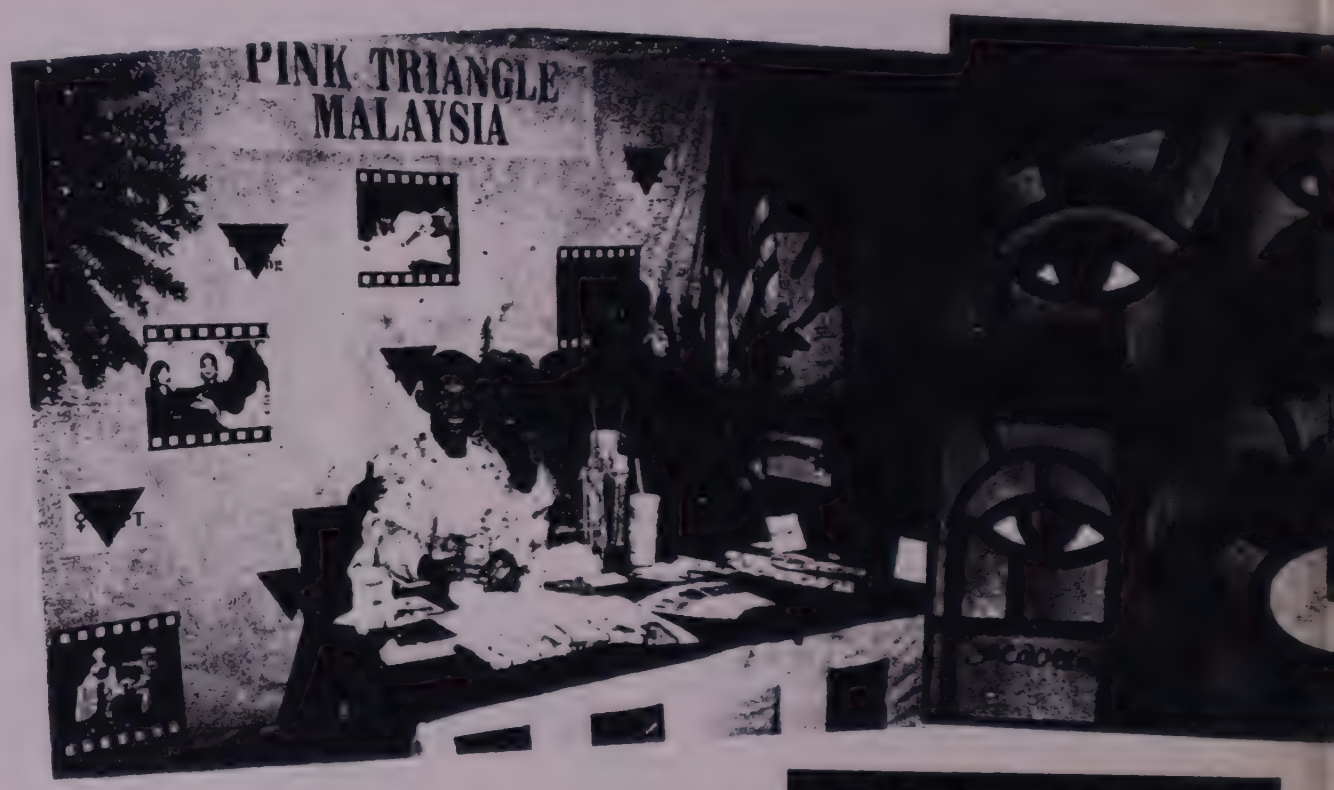
18.1.

MICHAEL L. TAN

The 11th International Conference on AIDS was held in Vancouver, Canada from July 7 to 11, 1996, with about 15,000 participants from 125 countries. The conference was preceded by media reports about breakthroughs in drug therapy, particularly around a new group of anti-HIV drugs called protease inhibitors. The last international AIDS conference was held in 1994 in Yokohama, Japan, and was marked with more pessimism following disappointing results with a large clinical trial involving the use of zidovudine (AZT). How realistic then was Vancouver's theme of "One World, One Hope," especially for Asia and the Pacific? What was, and was not, featured in the global news agencies' releases, and why? The following summary of the conference highlights should help you to decide.

Epidemiology

At the conference, a report released by UNAIDS (Joint UN Programme on HIV/AIDS), Family Health International and the Harvard Medical School evaluated the status and trends of the HIV epidemic. Globally, it is now estimated that there are some 22 million people living with HIV and AIDS, including some 21 million adults and 800,000 children. About 94 percent of people living with HIV are in developing countries. The pandemic is estimated to grow at the rate of about 7,000 new infections per day, or about five new infections per minute. Since the beginning of the epidemic, almost 6 million people have died from HIV and AIDS.



The Conference logo (at right), and one of the NGO booths at the conference exhibit.

The report did have some good news: infection rates seem to have "stabilized" or are decreasing in some developed countries, including the United States, Australia and New Zealand. There is also evidence that in countries like Uganda and Thailand, HIV prevention efforts may be slowing down the epidemic at least with some population groups. At the same time, infection rates are rising rapidly in many developing countries. In Asia, there is great concern over the increasing rates in countries like India, Cambodia and Myanmar. Despite comparatively low prevalence rates, India now has the world's largest number of people with HIV/AIDS simply because of its large population. Again showing how HIV is a disease of development, infection rates continue to rise among certain populations in developed countries. In the United States, these include "communities of color," i.e., minority groups such as Blacks and Hispanics, who continue to be unreached by effective HIV prevention programs.

Basic Research about HIV: Viral Loads, HIV Subtypes, and Chemokines

Two areas of basic research dominated many of the discussions at the conference: (a) viral loads and (b) chemokines.

Since 1995, medical researchers in the United States have pushed for the use of viral loads as a way of monitoring HIV disease. "Viral loads" is a lay term which is not quite accurate. What it actually refers to is plasma viremia, or the levels of virus in the plasma. Using polymerase chain reaction (PCR) tests, it is possible to detect HIV RNA fragments

tic material) in the blood. By looking s viral load, it is possible now to up with a prognosis, i.e., evaluate atient's stage of HIV disease. For ple, in men with HIV-1 RNA levels han 4500 copies/ml of blood, about would be expected to survive for the five years while the median time for to develop would be about 7.8 . If the RNA levels are between 4501 3,000, the five-year survival rate falls 9% and the median time to AIDS d be 6.6 years. The use of viral load better predictor than CD4 cell (T4 lymphocyte) counts. Testing for viral load also allows for monitoring of the effects of drug treatment – a drug's efficacy would be monitored by the decrease in HIV viral load. The problem with viral load testing comes mainly with its high cost.

There were several papers on the distribution of HIV-1 subtypes. There are now ten subtypes of HIV-1 that have been identified: A to I and O. These have specific geographic distribution. For example, subtype B dominates in Europe and North America. In Thailand and parts of theast Asia, subtype E is identified t frequently. Papers at the Vancouver erence did show that there seems to trend toward mixing of these ypes. Thus, one study showed that o a third of the identified subtypes patients in Germany are now non-., subtypes from Asia and Africa are more frequent. Dual infections with ypes B and E are also now being rted.

There is concern that this rnational mixing could mean changes e epidemic's transmission patterns. types from Asia and Africa, for nple, seem to be transmitted more iently through heterosexual contact. mixing of subtypes also means that ine research would have to be reoriented. At present, vaccine products are based on subtype B and therefore may not be effective to protect against other subtypes that occur around the world.

Clearly, HIV-1 is marked by great genetic variation, not just across countries but also in individuals. Researchers reiterated earlier findings showing rapid mutation in the virus, including resistance to drugs.

The other focus of basic science papers was on chemokines (also known as cytokines). Until recently, HIV's destructive action was attributed to its being able to bind itself to CD4 receptors in T-cells in the blood, which are important in the body's immune system. Recent research shows that HIV also binds itself to receptor sites on chemokines, which are chemicals in the body that attract immune cells to sites of infection. HIV's target would therefore be cells that have both CD4 and chemokine (more specifically, CC-CKR-5) receptors. These findings are important for the development of future drugs since it means that there are now two co-receptor sites that should be blocked as part of an anti-HIV treatment. Other researchers warned that more research is needed on other possible suppressors of HIV replication. Jay Levy of the University of California said CD8+ cells from long-term nonprogressors (people infected with HIV but who have not developed AIDS) have a substance that seems to inhibit HIV replication, at least in the laboratory. Levy called this substance CD8 antiviral factor (CAF).

Drugs

The use of protease inhibitors in the treatment of HIV drew the most media attention. Over the years, a number of drugs called reverse transcriptase inhibitors (e.g., zidovudine, didanosine) have been developed against HIV. These drugs work by interrupting the process of copying or transcribing HIV's genetic material. The protease inhibitors work on another phase of HIV's reproduction: the assembly of the new virus after the genetic material has been copied. Logically, combining reverse transcriptase inhibitors and protease inhibitors may offer better chances of working against HIV because it affects different phases of HIV reproduction. Since December 1995, three protease inhibitors have been approved (see box).

A small study conducted at the Aaron Diamond AIDS Research Center showed that the use of three anti-HIV drugs – zidovudine, 3TC and ritonanvir – resulted in aviremia, i.e., there was no evidence of viral reproduction in the blood. However, the study involved only 12 patients, of whom only nine remained with the trial.

Shortly before the conference started, a panel of experts released a consensus statement of antiretroviral therapy for HIV infection.

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Antiretroviral Drugs

Nucleoside Analog Reverse Transcriptase Inhibitors

Zidovudine (ZDV, AZT, Retrovir)
didanosine (ddI, dideoxynosine, Videx)
zalcitabine (ddC, dideoxycytidine, Hivid)
stavudine (d4T, Zerit)
lamivudine (3TC, Epivir)

Non-Nucleoside Reverse Transcriptase Inhibitors

nevirapine (Viramune)

Protease Inhibitors

saquinavir (Invirase)
ritonavir (Norvir)
indinavir (Crixivan)

published in a special issue of the Journal of the American Medical Association, stating that "as many as 85 percent of patients treated with drug combinations that include the new protease inhibitors could achieve undetectable levels of plasma HIV." The optimistic mood of the statement seemed to be shared by other medical researchers, who are now using terms such as "suppression" and even "eradication" when referring to the action of the drugs on the virus. There were even suggestions that HIV disease might soon become another chronic disease, where medicines could be used to postpone, indefinitely, the development of AIDS.

Other medical researchers are more cautious. Dr. David Ho of the Aaron Diamond AIDS Research Center suggests that anti-HIV therapy may need to focus on different "compartments" of HIV infection: free virion (virus particles); infected cells; T-cells that carry latent infection and macrophages that harbor HIV. Treating the macrophages, which are long-lived, may be the most difficult, requiring up to 3 years of treatment. He also said that it is not clear if there are other "sanctuaries" where HIV may remain, for example in the central nervous system. If such sites exist, treatment would be more difficult since existing anti-HIV drugs are not able to penetrate the blood-brain barrier.

Clearly, "viral eradication" will not be easy . The drugs are all capable of causing serious side effects, which means that long-term therapy will be very difficult. Viral resistance to the drugs also develops rapidly, even when different drugs are combined. Finally, there is the high cost of the drugs. Each of the new protease inhibitors would cost from US$6000 to $8000 per year, an amount which is considered high even by people living in developed countries. Anger and frustration over the lack of access to these medicines were expressed both by North American AIDS activists as well as by delegates from developing countries.

While tuberculosis is now recognized as the most common opportunistic infection in AIDS, there were few papers presented on the disease. The papers that were presented focused on drugs, mainly the growing problem of resistance to anti-tuberculosis drugs.

Prevention Technologies and Programs

With so much focus on antiretroviral drugs, it was not surprising that less attention was given to work on the development of technologies to prevent the disease.

Dr. Christopher Elias of the Population Council gave a plenary presentation on female-controlled methods to prevent sexual transmission of HIV. Elias noted that AIDS is now the third leading cause of death in the United States for women aged 25 to 44 (and the leading cause of death among African-American women). Elias said that "...nonconsensual sex, the fear of domestic violence or economic abandonment, and difficulties in initiating or sustaining discussion concerning condom use greatly limited many women's prevention options."

Elias noted that female condoms have been available since 1992 and that these seem to be effective against HIV. Elias described current research on microbicides, substances that could inhibit or kill HIV and other microorganisms causing sexually-transmitted diseases. These include older spermicides such as nonoxynol, octoxynol and menfegol. The problem with these spermicides is that they are detergents and can be irritating in the genital tract. Despite widespread promotion of nonoxynol as a method to prevent HIV, Elias noted that there is still no consensus about the chemical's role in preventing HIV. Research is now ongoing to develop new chemicals or reformulate the older ones. The development here is quite slow since there is still little interest from private companies, who do not see these microbicides

ing commercially viable. Such cts may therefore not be available next few years. Elias emphasized any female-controlled method d be seen as a complement to male nsibility.

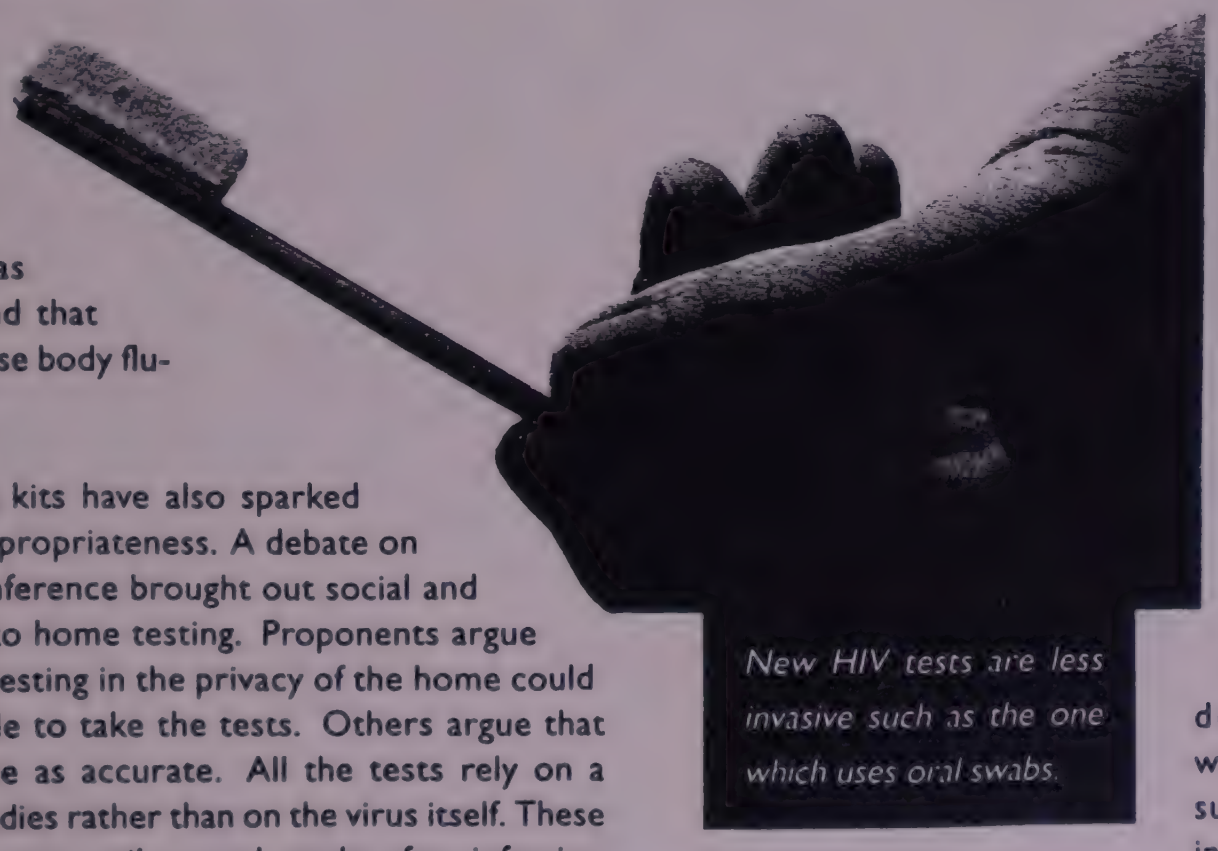
There was renewed interest in the f zidovudine, this time for reducing risk of perinatal infection. Dr. nne Bryson, who delivered a ry paper on perinatal infection, d that studies show zidovudine can ce, by as much as 67 percent, the perinatal infection rate. However, women with HIV would have to start taking the drugs when they are 16 weeks pregnant. The costs are, again, substantial.

Several papers in the conference focused on the need to integrate different services, and technologies, for preventing HIV. These related mainly to the integration of reproductive health services, particularly family planning and the prevention of sexually transmitted diseases (STDs). One paper showed that in Malawi, HIV levels in the semen were much higher in patients with urethritis (caused usually by gonorrhea and trichomonas). Two weeks after treatment, the semen viral loads in these men decreased. This could reduce the infection rates.

One last non-biomedical form of technology received increasing recognition for its potential in HIV prevention: information technologies. Several skills-building workshops demonstrated how information can be accessed rapidly through the Internet and related services.

New Tests

The conference became an occasion to publicize new HIV body tests, including those that can be used for home test- (The home testing kits allow for collection of samples at e but the sample still has to be sent to a laboratory for ng.) Most testing today uses blood but the new kits are to detect HIV antibodies in saliva as well. (Shortly after conference, a e test was also oved by the US d and Drug Ad- stration.) The s using saliva and e are promoted as g easier to use and that are safer since these body flu- re not infectious.



New HIV tests are less invasive such as the one which uses oral swabs.

The home testing kits have also sparked lebates on their appropriateness. A debate on first day of the conference brought out social and cal issues relating to home testing. Proponents argue the availability of testing in the privacy of the home could burage more people to take the tests. Others argue that e tests may not be as accurate. All the tests rely on a ction of HIV antibodies rather than on the virus itself. These bodies may not appear until several weeks after infection so-called window period). Thus, false negatives are possi- There are fears, too, that home testing might not be ap- riate because of the lack of appropriate pre- and post-test nselling. Would such tests open the way to abuse by po- border guards, employers or even sexual partners who t use such tests indiscriminately?

None of the debates tackled the implications of saliva and e tests for HIV education. Given that the tests are used to detect HIV infection, lay people might easily become confused and think that saliva and urine can transmit HIV. Great caution is therefore needed to explain that levels of HIV in blood and urine are not infectious.

The availability of new, less expensive tests, coupled with the introduction of new antiretroviral drugs is sure to spark more debates about testing. Increasingly, AIDS groups in developed countries are recommending testing on the premise that early detection will mean early treatment. Such arguments may not always apply to developing countries, where treatment and other support services are still inaccessible. There are also concerns about such tests in developing countries where there are less guarantees of anonymity and informed consent. Michael Merson, who used to head the World Health Organization's Global Program on AIDS, recommended that policies on testing should be based on "sound and scientific data and in consultation with consumers." He also recommended that home HIV testing should focus on screening rather than on diagnosis.

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Mobilizing Communities

UNAIDS' Purnima Mane, who delivered a summary of the sessions and papers on social and behavioral sciences at the closing ceremony, noted that "Everything that needs to be said has been said. Since no one listened the first time it was said, it needs to be said again."

Earlier in the conference, Richard Parker delivered a plenary speech that in many ways set the tone for discussions on policies. Parker talked about the shifts in models, away from information-driven programs seeking individual change and toward multi-dimensional models of collective empowerment and community mobilization.

Parker noted that early in the epidemic, prevention programs had to say that everyone was vulnerable to HIV. This was a

" necessary fiction " to move away from the idea of "high-risk groups." At the same time, this tended to obscure the fact that some people are more vulnerable to HIV because of oppression, exploitation, and violence.

Parker argued that it is possible to aim both for individual behavioral change and social change, and that one must recognize how science, politics and ethics are all mutually implicated in all we do.

There were in fact several sessions marked by debate around political and ethical issues. Several presentations showed how a needle exchange program – giving clean syringes and needles to injecting drug users – could decrease infection rates. Yet in many countries, including the United States, this option has not been implemented because of opposition from conservatives who argue that the program would only encourage drug use.

One panel discussion on "AIDS, Politics and Inequality" tackled global political and economic issues. Meurig Horton of the United Kingdom said that activities of transnational corporations, assisted by policies of the International Monetary Fund and the World Bank, have imposed reductions on governments' budgets for social services and that these impact on the HIV epidemic. Horton noted that "People are considered worthy of health care only if they are considered economically productive contributing to the global economy." He observed that the World Bank is now more influential in defining global health policies than the World Health Organization and that priorities for AIDS programs depend on whether they represent priority growth markets for western consumer markets.

The heated discussions about politics and inequality were matched by the very active participation of AIDS activist groups. Members of the militant ACT-UP were active in demonstrations during the opening and closing ceremonies as well as in several plenary sessions. They also conducted daily demonstrations against drug companies, accusing them of profiteering from the epidemic.

The conference was marked by greater visibility of NGOs, particularly organizations of people living with HIV/AIDS (PLHA). Both at the opening and closing ceremonies, there were several speakers from such organizations. At the opening ceremonies, Doreen Millman, a silver-haired Canadian, courageously addressed thousands of delegates, declaring she had HIV and asking, "You're wondering how someone like me, a 63 year-old grandmother, got infected." After a brief pause, she continued: "The answer is very simple... It just doesn't matter."

At the closing ceremonies, an Indonesian PWA, Susana Murni, stunned the audience when she started her speech by rejecting the call of a previous speaker to "fast-track" medicines in developing countries. Murni said the call was "offensive and

ting" and that Third World people were not to be guinea for drug experiments. It was an eloquent contribution to the erence with a message that rejected condescending pity.

The NGOs continued a tradition of holding a community m before the conference. The Vancouver forum resulted in formation of a global working group of NGOs concerned the protection of human rights of persons living with HIV/ S. Another working group called for global standards in tment and care. A third group recommended the integration esearch into community programs while a last group mmended that national AIDS programs should allocate at least ercent of their funds to NGOs and community-based groups.

As the conference came to a close, the distinction between

"Everything that needs to be said has been said. Since no one listened the first time it was said, it needs to be said again."

"biomedical" and "political" issues became artificial. At the closing ceremonies, Dr. Michael O'Shaughnessy presented a summary of Track B (Clinical Medicine) papers. He noted one paper showing that Africans with AIDS, in London had better survival rates than other population groups. Thus, the poor outcome of African patients in Africa was clearly related to a lack of access to services. O"Shaughnessy said the problem cannot be fixed by drugs alone. He concluded his presentation: " We speak of one world, but in reality we are worlds apart."

The joint report from UNAIDS, Family Health International and Harvard Medical School notes that ". . . the HIV/AIDS pandemic is now composed of distinct epidemics each with their own features and force, and disproportionately impacting on the developing world." The conclusion, drawn from cold epidemiological statistics, should force governments and NGOs to seriously look into the reasons why such distinctions have emerged.

Effective HIV/AIDS activities: NGO work in developing countries. Report of the Collaborative Study. UK NGO AIDS Consortium. 1996. This report summarizes highlights from evaluation studies of 19 field organisations in developing countries and 13 agencies based in the United Kingdom. The report shows how different methodologies can be used to evaluate various types of HIV/AIDS activities in the areas of prevention and care. The methodologies used include focus groups; individual and family interviews; costing analysis and process documentation of projects in various stages of implementation. One important lesson from the collaborative study was the need to analyze HIV/AIDS activities in relation to organisational structure and effectiveness. Among the participating organisations were six organisations from India, Thailand and the Philippines. Other countries represented were Ghana, Uganda, Zambia, Zimbabwe and Brazil. Copies of the report are available from the UK N GO AIDS Consortium, 37-39 Great Guildford Street, London SE1 0ES, United Kingdom.

Broadening the front : NGO responses to HIV and AIDS in India by J Shreedhar with A Colaco. 1996. Describes the pioneering work of seven India NGOs in response to the HIV epidemic in India. Limited copies are free for developing countries, £2.75/copy elsewhere. Available from TALC, P.O. Box 49, St. Albans, Herts, AL1 5TX, UK.

Evaluating HIV/AIDS health promotion. P Aggleton, D Moody, A Young. 1992. A resource for HIV/AIDS health promotion workers in health authorities, local authorities and voluntary organisations. Available from Health Education Authority c/o Marston Book /Services Ltd, P.O. Box 87 Oxford OX2 0DT, UK. £10.95.

HIV/AIDS project planning manual for NGOs. J Huddart. 1993. Manual for non-governmental organisations working in AIDS with information that can assist in improving planning and project development skills. Available free from UNDP, Regional Projects on HIV/AIDS, 55 Lodi Estate, New Delhi 110 003, India.

Tools for project evaluation : a guide for evaluating AIDS prevention interventions. 1992. Reviews evaluation methodologies with suggestions for evaluating HIV/AIDS projects in developing countries. Includes guidelines and a bibliography for further reading. Available for free from AIDSTECH/Family Health International, P.O. Box 13950, Research Triangle Park, Durham, NC 27709, USA.

Toolkits is a guide for the assessment, monitoring, review and evaluation of the impact of a development programmed on people's lives. A practical aid for development workers offering tools for participatory rural assessment (PRA) and logical frameworks analysis (LFA) which can be used at different stages of the process, and adapted to different situations. Available in English from Save the Children, Publication Sales, 17 Grove Lane, London SE5 8RD, UK. £6.95 plus 15% for postage and packing.

Community HIV prevention handbook covers the key steps for action planning with communities. For more details contact UNAIDS, 1211 Geneva 27, Switzerland.

Manual of group interview techniques to assess the needs of people with AIDS gives guidelines on running group interviews to plan HIV care programmes. Available free from WHO Documentation Centre, 1211 Geneva 27, Switzerland.

Partners in evaluation is a practical handbook for community-based programmes on monitoring and evaluation with local communities. Available for £3.20 from TALC, P.O. Box 49, St. Albans, AL1 4AX UK.

Self-evaluation is a simple guide for rural community development programmes. Available for US$5.00 plus postage from World Neighbours, 4127 NW 122 Street, Oklahoma City, OK 73112, USA.

New Resources

Stepping stones is a training package on HIV/AIDS, gender, relationships and communication skills for running workshops with community members. Available for £85.00 (4 manuals 1 video), £47.50 (1 manual 1 video) or £12.50 (manual only) from TALC. Contact TALC for details of Swahili, Luganda and French language editions. Limited copies free to orgnisations in Sub-Saharan Africa on written request to TALC.

Facing the challenges of HIV/AIDS/ STDs: a gender-based response contains an outline of the issues that affect women and men, and practical training exercises. Available free from KIT, Mauritskade 63, Amsterdam 1092 AD, The Netherlands.

For more information on HIV/AIDS, gender issues, and sexual and reproductive health, you may contact:

HIV/AIDS Inquiry Services
AIDS Action Asia-Pacific
9 Cabanatuan Road
Philam Homes 1104, Quezon City
Philippines
Telephones: (632) 927-67-60 or 929-88-05
Fax: (632) 927-67-60
Email: hain@mnl.sequel.net
Web site: http://www.hain.org

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11

MATERIAL ON HIV/AIDS

SENT BY

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AIDS AND INTERNATIONAL HEALTH DEPARTMENT

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EDUCATION FOR LIFE
A BEHAVIOUR PROCESS
FOR GROUPS

INTRODUCTION

WHY "EDUCATION FOR LIFE"?

In the beginning of the AIDS pandemic, a great effort was made to ensure that all people had sufficient information about the disease to protect their lives and to prevent the spread of the virus. There was a heavy emphasis on mass media messages, posters, and input sessions. All of this was necessary. However, just as with all public health programmes, as the years have passed, it has become evident that information on its own is not enough to bring about behavior change.

> MORE IS NEEDED THAN SIMPLY INFORMATION
> AND/OR THE PRESENCE OF FEAR.

This process, called "Education for Life", is an attempt to provide that "more" and to assist those with information about AIDS to take the next important step.

The PREVENTION OF AIDS is a CALL TO LIFE, the life of the whole person. This person is a sexual being, not just a person who has sex. Thus, any effective preventative programme must take this into account and deal with the person's whole life. This life is dynamic, always changing. It must change if the person is to grow.

"TO CHANGE IS TO GROW.

TO GROW IS TO CHANGE OFTEN."

Change is normal; behaviour change is normal; change of sexual behaviour is normal. It is a process of growing into freedom of choice and intimacy; a process of becoming more fully human.

However, many people seem to have a defeatist approach to the change of behavior, especially sexual behaviour. It is often assumed that people cannot change their behaviour, and prevention strategies have been designed based on that assumption. It is not true. Human beings do have the inherent capacity to change, and given help and encouragement, can and do change. Experience has proved this. Unfortunately, the voices of people with this experience are not often heard.

In December, 1991, a group of people were called together in Dakar, Senegal to explore the whole issue of behaviour change as preventative strategy. From the shared experience of this group the following Statement of Belief.

STATEMENT OF BELIEF

WE BELIEVE THAT INDIVIDUALS AND WHOLE COMMUNITIES HAVE THE INHERENT CAPACITY TO CHANGE ATTITUDES AND BEHAVIOURS. THE POWER TO FULFILL THIS CAPACITY IS OFTEN DENIED OR IS NOT EXERCISED.

THIS POWER MUST NOW BE RECOGNISED, CALLED FORTH AND SUPPORTED FROM BOTH WITHIN AND WITHOUT. THIS WILL ENABLE PEOPLE TO INITIATE AND SUSTAIN BEHAVIOURS THAT PROMOTE A HEALTHY STATE OF MIND, BODY, SPIRIT AND ENVIRONMENT. A CRITICAL COMPONENT IN THIS PROCESS IS A SUPPORTIVE RESPONSE TO THOSE LIVING WITH HIV IN THE COMMUNITY.

WE RECOGNISE THAT BEHAVIOUR CHANGE AT INDIVIDUAL AND COMMUNITY LEVEL IN THE PRESENT HIV PANDEMIC IS A COMPLEX AND ON-GOING PROCESS. IT IS INEXTRICABLY LINKED TO SUCH BASIC HUMAN VALUES AS CARE, LOVE, FAITH, FAMILY AND FRIENDSHIP, RESPECT FOR PEOPLE AND CULTURES, SOLIDARITY AND SUPPORT.

THE PRESENT PANDEMIC AFFECTS EVERYONE. OUR EXPERIENCE AS AFFECTED AND INFECTED INDIVIDUALS PROVES THAT BEHAVIOUR CHANGE IS POSSIBLE. WE BELIEVE THAT BEHAVIOUR CHANGE IS THE MOST ESSENTIAL STRATEGY IN OVERCOMING THE HIV PANDEMIC.

This statement confirms the need to promote the "Education for Life" Programme.

HISTORY OF THE EDUCATION FOR LIFE PROCESS

Crisis situations often stimulate inspiration. This is proved true in the following narrative by Sr. Kay Lawlor.

> In 1988 duriny a celebration at Kalungu Secondary School (Masaka, Uganda), a school where several seminars had already been held on AIDS, I was suggesting another session of input for the new students when the headmistress surprised me by saying, "I can't listen to one more talk on AIDS. You people come here and tell us how it is transmitted and how fast it is spreading and each time the statistics get worse. No one is helping us to stop it." This quite shocked me and I began to get defensive, saying: "it's not possible to stop it if the people themselves won't change their behavior". "Help them to do it then", she said. I went away with that statement ringing in my ears.

Several days later I realized that I was stlll defending myself and our programmes in my mind; it was not productive.It was then that I decided to try and solve the dilemma by applying the method of counselling that I used in the Pastoral Care and Counselling Department of Kitovu Hospital. It is a problem solving and action oriented approach based on the "helping skills" model of Gerard Egan (see Egan,G. "The Skilled Helper". Brooks/Cole Publishing Company, Monterey, California, 1986.). A key facet of the model is the ongoing evaluation of the process;

> ONE NEVER FAILS UNLESS ONE STOPS TRYING

In order to learn from the "apparent" failure of the approach at Kalungu, I needed to look more closely at the problem in a systemic way.

I looked first at the present reality and saw that we were stuck in giving the same information over and over again to as many groups as possible. The message was getting to the people but change wasn't occurring in their behavior. Were we missing something? Yes. In stressing the facts about AIDS, emphasis was being placed on the disease and not on the underlying behavior. There was no help given to them to look at the social, economic, cultural, and psychological stresses underlying their actions. Most people believe deep down that they had very little choice. The focus needed to be shifted. Like most people when they reach this stage, I wanted concrete solutions. However, by staying with the process I began first to surface possibilities and to assess their usefulness. Drama, role plays, discussions, all came to mind; most were already being used. What was missing was an ongoing process which utilized the principles of behavior change; a process that would take place in

a group. As I worked on this it became clear that I could use the same "helping skills" model in our preventative work that I was using to try and solve this problem. With this the "Education for Life" process was born.

The teachers at Kalungu were most enthusiastic and cooperative. A Programme was drawn up, enfleshing the Process and training sessions were held for group leaders. Students met in small groups with a group leader once a week and followed guide questions which kept them on track with the process. This was the concrete beginning.

Since then, the use of the "Education for Life" Process has been incorporated into many different programmes; it has grown, spread and been greatly enriched. Throughout this time, the underlying process has remained the same while the way it has been enfleshed in programmes has varied greatly.

Groups such as Basic Christian Communities, Community Based Health Care Programmes, Parishes, Youth Clubs, Family Life Teams, hospital departments, schools, and government agencies have used the process creatively and enthusiastically. It has been used in classrooms, in the training of Ugandan UNICEF-sponsored health educators, in the Muslim community, in industry; wherever people are in need of help in preventing AIDS.

It has been noticed over the years that the groups making the most consistent and effective use of the process have recognized and incorporated an element necessary for bringing about a SUSTAINABLE CHANGE; the element of FAITH. This is a reference to and a dependence on a Higher Power, a Spiritual Source, God; however an individual understands this.

By early 1995 it became evident that the use of the "Education for Life" Process had begun to spread rapidly and in varying directions, It needed to be assessed and updated. The booklet also needed to be redrafted to make it more useful to those interested in integrating this approach into their programmes. Thus, in April, 1995 a small group of people experienced in the use of the "Education for Life" Process met and shared their experience. What works? Where are the problems? What have we added? How have we enfleshed it? How can we make the booklet clearer for others? Out of this sharing and evaluation this revised version of the "Education for Life" manual has been produced.

For this sharing and help, special recognition and gratitude are given to:

Sr. Doreen	Comboni Missionary, Gulu
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THANK YOU

UNDERSTANDING BEHAVIOR CHANGE

This is not intended to be a complete review of the subject of behavior change; it is simply a look at some of the principles and factors underlying the "Education for Life" programme, and which help to concretize the Dakar Statement.

GROUP PROCESS IS IMPORTANT

During our lives we learn ways of behaving mainly from those around us. This learning begins with conception; it is further influenced by the situation surrounding our birth: and throughout life it is constantly being affected by family, friends, education, faith and environment - all that surrounds us.

Each person is unique, with an unique experience and unique opportunity to grow. At the same time, each person is immersed in community and social groups. It is that fact that led to considering working mainly with a group process. Especially when we talk about the youth, peer pressure takes on a prominent role. It is easier to change and maintain behaviors when there is support of a group.

BEHAVIOUR CHANGE IS DIFFICULT - WHY?

It is common knowledge that it is not easy to change one's behaviour. There are no easy answers to why this is so; it is a complex problem. However, there are conditions that can be recognized as affecting the ease or difficulty of change. In simple terms, behaviour is hard to change because our present behaviour is:

1. A HABIT

As behaviors are repeated, habits are formed. The stronger the habit, the harder it is to break it. Everyone has habits they have tried to break without much success. Motivation is important; the person must want or admit to the need to change. The process used to change is also important. Often we can discover this process by examining the habits that we ourselves have managed to change.

2. COMFORTABLE

Human beings choose behavior that leads to comfort; it takes strong motivation to choose what is uncomfortable. Abstaining from sexual intercourse is seen as uncomfortable by many. Young people are very aware of their sexual feelings and energies; they often see abstinence as painful and as a deprivation. For adults the refusal to have sex may result in loss of livelihood, spouse or partner, or sense of identity; all of which is seen as uncomfortable.

3. WITHOUT RESISTANCE

Familiar behavior occurs without resistance; any attempt to change meets with resistance.

4. REWARDED

People often repeat behaviours that are rewarded and avoid those that are punished. This appears a simple fact at first but in AIDS prevention it becomes very complex; only the person concerned really knows what is reward or punishment for him/her. Culture, gender economic condition, education, and many other factors come into play here. Women have often been heard saying that they would rather have a child and die young than to live to an old age childless; the child is a greater reward than their own life.

5. SELF-CHOSEN

The "child" inside of each person fights to maintain autonomy and resists changes that are seen to be imposed by another. This again is especially true of young people. They are in the process of determining their own identity and accepting boundaries for their actions; independence is important to them as they

consider it a sign of being "grown up".

The true sign of being grown up is the ability to make free responsible choices. THIS IS TRUE FREEDOM. Today, many people operate out of licence which often is an enslavement to public opinion, peer pressure or social dictation.

All of this can be summed up by a few key words:

GROUP***COMFORT***REWARD***HABIT***RESISTANCE***SELF-CHOSEN

An understanding of these words is essential to behavior change.

Also essential is the BELIEF THAT CHANGE IS POSSIBLE. Without this belief, one will not even begin to try to change or to help another to change.

III. HOW BEHAVIOUR CHANGES

A process is a series of stages moving towards a definite goal. Behaviour change is a complex process that can be broken down into a three major stages:

1. Know and accept the present reality (behaviour);

2. Choose and commit self to a possible new behaviour;

3. Act!

These 3 stages form the basis of the behaviour change process. It is an ongoing process and ONE NEVER FAILS AS LONG AS ONE KEEPS TRYING. This phrase is repeated often in this booklet. It is the key to the use of "Education for Life". Life is dynamic; one is always in process of change.

IV. BELIEF IS ESSENTIAL

None of this can occur without the basic belief and attitude that CHANGE IS POSSIBLE.

THE BASIC BELIEF IS:

I NEED TO CHANGE

I HAVE THE CAPACITY TO CHANGE

I CAN CALL ON THE SPIRITUAL POWER TO CHANGE.

V. HELPING OTHERS TO CHANGE

To help another person change, we help then move through the three stages mentioned above. This requires not only the belief that the person can change, but also the willingness and ability to accept and support the person every step of the way, especially in THAT PERSON'S choice of new behaviour. Unless the person believes change is possible, wants to change, and finds some reward in the new behaviour, change will not occur. And unless the helper has positive

attitudes and helping skills, the necessary helping relationship will not be formed. This will be dealt with in more detail in the section on training and preparation.

A HELPER MUST BELIEVE

PEOPLE CAN CHANGE THEIR BEHAVIOUR IF HELPED

THE FURTHER SPREAD OF AIDS CAN BE PREVENTED

THOSE WITH HIV INFECTION CAN LIVE POSITIVELY

MODEL OF CHANGE

Introduction

In the previous section we saw that change comes about in three stages. This forms the basis of the "Education for Life" process. It is based on the 'helping skills' model of Gerard Egan which is a behavioural and problem-solving approach. As used here, it is designed to facilitate a person's movement through the various stages involved in the changing of behaviour.

Overview of The Process

The stages of the current model are another way of stating what was seen in the section "Understanding Behaviour".

Stage I - EXPLORING LIFE (similar to knowing and accepting the present reality). It is facilitated by:

a) telling the story
b) focusing
c) looking for what has been overlooked.

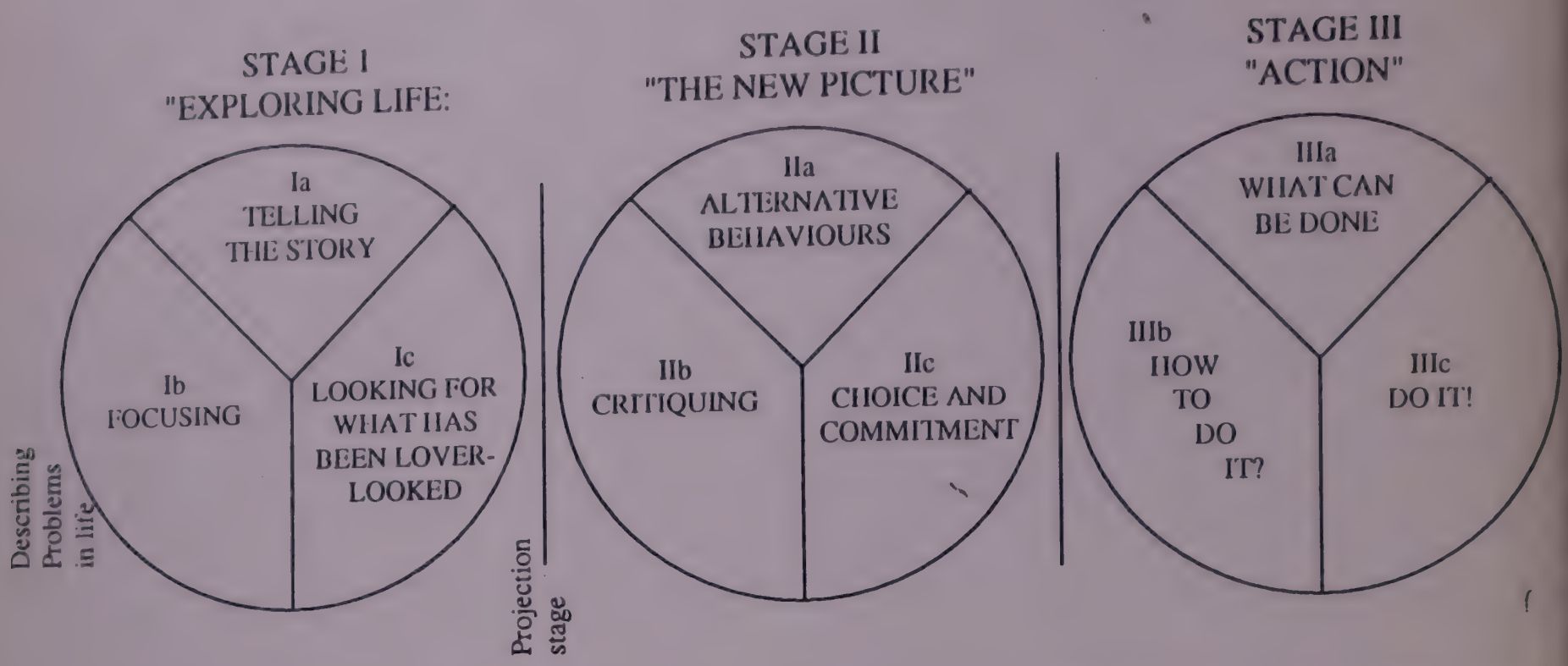
Stage II - THE NEW PICTURE (similar to choosing and committing oneself to possible new behaviour). It is facilitated by:

a) calling forth alternative goals
b) critiquing them
c) making choices and commitments

Stage III - ACTION (similar to act). It is facilitated by:

a) asking what can be done
b) planning how to do it
c) doing it.

This can be visualised in the following diagram:



As described, each stage has three components which assist one to go through that stage progressively. Each stage will now be looked at in depth.

STAGE I - EXPLORING LIFE

STAGE Ia - Telling the story

Behaviour never takes place in a vacuum; it is always the behaviour of a person with a unique background and environment. Therefore, it is important to explore life experiences of the persons involved in the process. There are often hidden causes that need to be identified. This occurs through a guided telling of one's story. It is kept general at first to ensure a full picture and also to allow the gradual building of trust and a feeling of safety.

The following questions and those of like nature assist in working through Stage Ia. More will be said about the use of the questions in the section, "How to Use The Model".

QUESTIONS FOR STAGE 1a

GENERAL QUESTIONS

What is your life like today?
What pressures are put on you and by WHOM?
What do you value most?
What makes you angry, sad, or hurt?
What are the falsehoods and contradictions in life around you?
What makes your life easy?
What makes your life difficult?
Do you feel you are a free person? Why?
Who is God for you?
What in your tradition helps you most and what causes you problems?
What are your values and how do they influence you?
How do you experience family life?
How do you enjoy yourself?

QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH

How do you know you are popular?
Who are your friends and why are they you friends?
How do you spend your free time?
Where do you get your values?
Why do young people take drugs and what effect does it have on them?
Where do they get the drugs?
What job opportunities are available? Are they easy to get into?
Where do you get your extra money?
What are your plans for the future?

AYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SEC'TION, " HOW TO USE THE ODEL".

At this point, the STAGE I circle looks like this.

NOTES BY USER OF THE PROCESS

Stage Ib - Focussing

Because the main means of transmission of HIV is sexual activity with an infected person, it is important to begin to help persons to focus or look more closely at this aspect of their behaviour. It is a sensitive subject, a sacred subject, and requires a respectful approach. People often find it difficult to discuss issues regarding sexual behaviour and many lack adequate understanding of the gift of human sexuality. They need help.

The following questions provide a guideline for looking more deeply at these issues within Stage Ib;

FOCUSING: WHAT IS ONE'S SEXUAL BEHAVIOUR LIKE?

QUESTIONS FOR STAGE Ib

GENERAL QUESTIONS

How do husbands and wives relate?

What happens at times of celebrations?

What do you mean when you say SEX?

What helps you form relationship?

What do you value most in marriage?

What do you know about your traditional sexual practices and beliefs?

~~GENERAL QUESTIONS~~

Can a man or woman be satisfied
with one partner? Give reasons.

Why do men/women seek many partners?

What do men/women say about sex when they are together?

Does your religious faith teach
about sex/sexual behaviour?
What? Do you agree?

How do you think, feel and act
if someone says that he/she will
not have sex outside of or before marriage?

QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH

What do you like/dislike about the opposite sex?

What are the disadvantages and the advantages of being a man/woman?

How many partners do you think a young person has while at school?

Can a girl or boy say "NO"? ~~QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH~~

What will it cost him/her?

Why do boys and girls have sex before marriage?

Who talks to you about sex and what do they tell you?

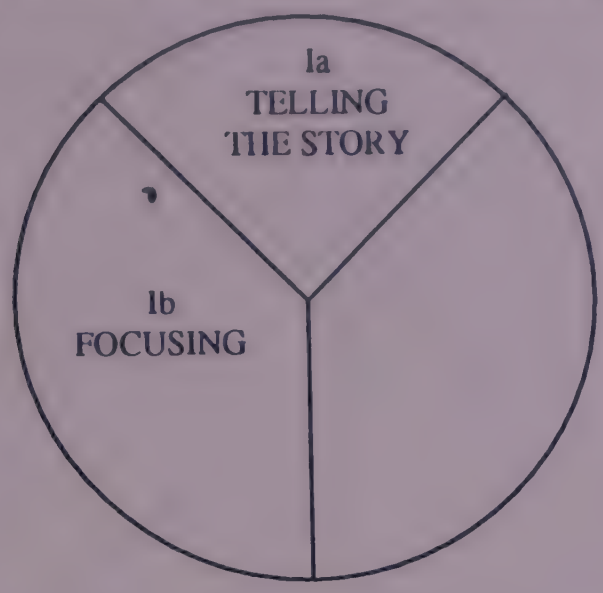
What happens at discos?

Can boys and girls be friends
without having sexual intercourse?

Where do young people get the sexual knowledge and experience?

AYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION " HOW TO USE THE ODEL " .

At this point the STAGE I circle looks like this:



NOTES BY USER OF THE PROCESS

Stage Ic - Looking for what has been overlooked

Many people continue with unsafe behaviour despite having heard many of the facts about AIDS. There are many reasons for this. Some deny the reality or pretend it isn't an issue for them; others have inadequate or inaccurate knowledge, and some have seen so much that they despair of being able to avoid the infection. For these reasons it is necessary to help people look more closely at the issue of AIDS as it relates to their lives.

The following questions are guides for insuring that HIV and AIDS are brought fully into the story of one's life:

BLINDSPOTS: WHAT ARE YOU OVERLOOKING? WHAT ABOUT AIDS?

QUESTIONS FOR STAGE Ic

GENERAL QUESTIONS

Is "playing sex" the real problem?

What do you and your friends believe about AIDS and sex?

What does your partner believe about your relationship?

What does a man/woman do when their wife/husband is unfaithful?

What do you think happens or should happen if one partner has the virus?

Do you think AIDS is a punishment from God? Give reasons.

What role does drinking play in the spread of AIDS?

What really causes AIDS?

Can AIDS be prevented? How?

What do you understand by "SAFER SEX"? Is it possible?

What traditional practices may spread AIDS?

How do you think, feel, and act when someone says that AIDS is a punishment from God?
What is the underlying cause of AIDS today?

QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH

Why do some young people continue to "play sex" if they know they can get AIDS?

What example does your family/our families give?

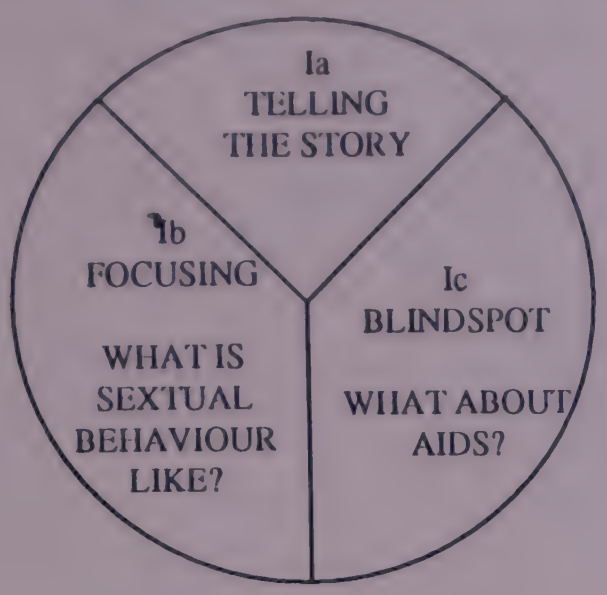
How do you think, feel, and act if a friend/loved one has been diagnosed with AIDS ?

How do you think, feel, and act if you know you have taken a risk?

Why do many young women have children but don't get married - even with the threat of AIDS?

AYS TO USE THESE QUESTIONS WILL BE DISCUSED IN THE NEXT SECTION, " HOW TO USE THE ODEL".

At this point the STAGE I circle looks like this:



The diagram of Stage I is now complete.

NOTES BY USER OF PROCESS

STAGE II - "THE NEW PICTURE"

Stage IIa - Calling Forth Alternative Goals

Many people fail to change behaviour because they do not consider alternatives. They are stuck. Even when they, or someone else, makes a suggestion, the first reaction is to say "...but it won't work for me". This Stage (IIa) challenges people to come up with a variety of alternatives WITHOUT making any judgements about whether or not they are possible. That will be done later. To judge at this point is to limit ones options. The task of IIa is to open up as many options as one can.

The following questions guide one in this open-ended approach. By answering them in a concrete way, AS IF THEY WERE ALREADY A REALITY, the person begins to sense that there is an alternative future.

QUESTIONS FOR STAGE IIa

NEW OR IDEAL PICTURE: WHAT DO YOU WANT YOUR LIFE TO BE LIKE?

N.B. THESE QUESTIONS ARE ASKED IN THE PRESENT TENSE - AS IF THE "PICTURE" IS ALREADY A REALITY.

GENERAL QUESTIONS

What is your life really like?

How are you getting your extra money?

How are you spending your free time?

What is the most important part of your relationships?

What is your relationship with your wife/husband/children like?

What challenges do you have?

What do you value most?

What attitudes have changed?

What importance does faith and religion have in your life? Where is God for you?

What is making you sad, happy, or hurt?

QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH

What is the most important thing in your life now?

How are boys and girls relating?

What values are influencing you?

Are you having fun and leisure now? How? Where?

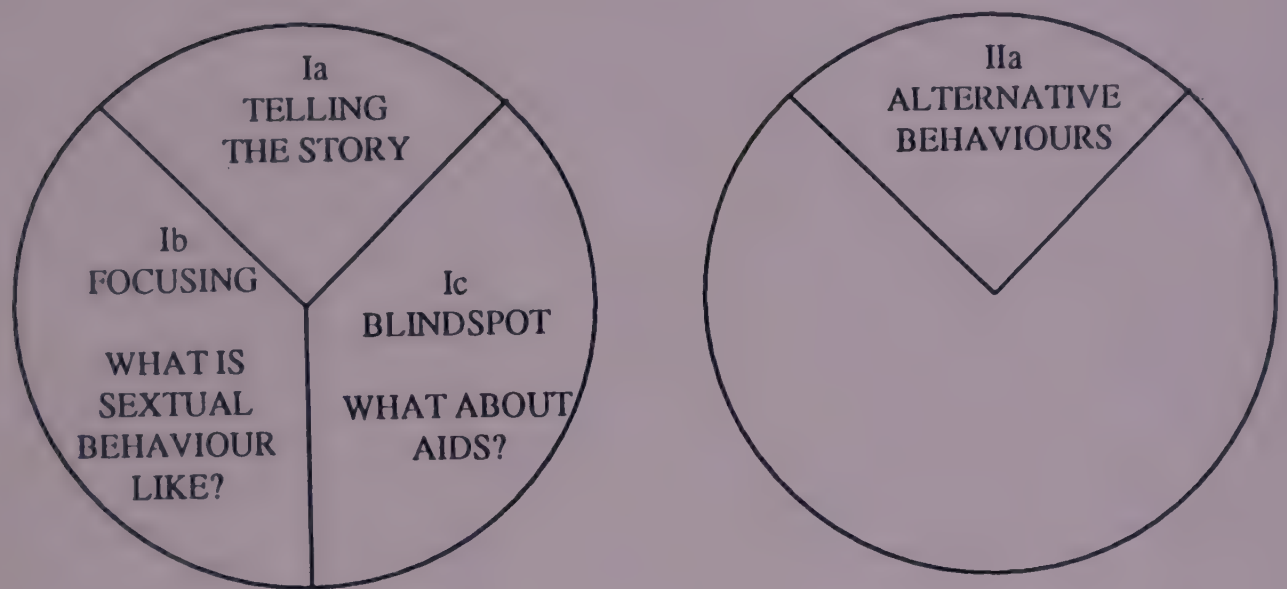
Where are you getting your knowledge of sex?

What part is sexual experience playing in your life?

AYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION, "HOW TO USE THE ODEL".

At this point the STAGE 11 circle looks like this:

The diagram of the Process now looks like this:



NOTES BY USER OF PROCESS

Stage IIb - Critiquing

Every alternative generated in Stage IIa will not be possible in the person's concrete situation. To simply try to choose and initiate a goal without looking at whether or not it is possible only results in failure and discouragement. In this stage, IIb, the person or group is helped to look at the implications of each alternative before making a choice.

The following questions assist in looking at all the alternatives:

IS THIS POSSIBLE?

QUESTIONS FOR STAGE IIb

GENERAL QUESTIONS

What will your wife/husband say about your choices?

What will your wife/husband say if you change?

Is your choice based on your values? What values?

What is the biggest obstacle to your changing?

What is the biggest pressure on you not to change?

Who can help you change and sustain that change?

'What would help you get rid of the obstacles and pressures?

What will make your change easier? More sustainable?

QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH

What will your friends say about your choices?

Will they remain your friends

What will your parents say about your choices? Is this important to you?

Are you proud of your choices and way of life?

WAYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION, "HOW TO USE THE MODEL".

At this point the STAGE TWO circle looks like this:

NOTES BY USER OF THE PROCESS

Stage IIc - Making Choices and Commitment

It is now time to decide just what "New Picture" or new behaviour is most suitable for a particular individual or group. It will be one which is not only possible but, one which the person or persons themselves feel they can stand behind. Once the choice is made, the person is helped to make a commitment to it. It is important that this stage of commitment be formalised; speaking it aloud, writing it, or ritualizing it in any other way is helpful. More will be said about this in the section "How to Use The Model".

The following questions will assist in making the most appropriate choice; one which will lead to commitment and change.

WHAT DO I CHOOSE TO DO? HOW WILL I MAKE MY COMMITMENT?

QUESTIONS FOR STAGE IIc

GENERAL QUESTIONS

What is the best and safest choice for you?

What will you say "yes" to?

What choice is in the best interest of your partner?

What choice is in the best interest of your family/children?

what choice will bring you the most happiness?

How will you express your choice?
Who will you tell about it?

QUESTIONS WHICH MAY BE MORE SUITABLE FOR YOUTH

What choice will give you the kind of adult life you want?

What makes you sad, hurt, happy?

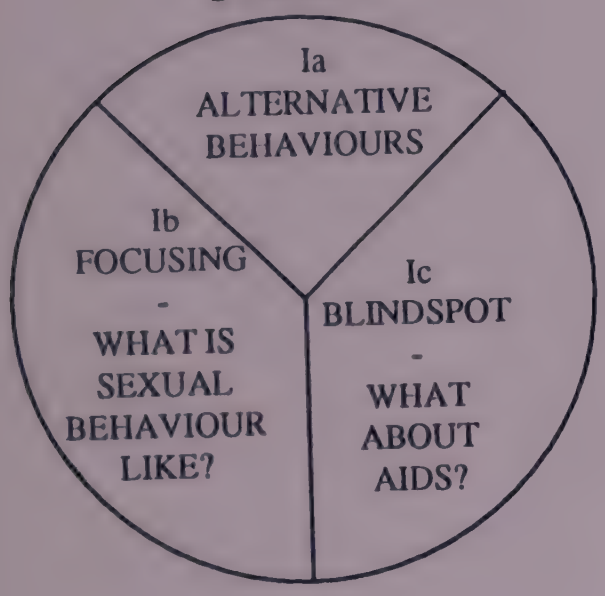
N.B. IT IS HELPFUL IF A PERSON/GROUP EXPRESS THEIR COMMITMENT ALOUD AND IN SOME SYMBOLIC OR RITUAL WAY. THIS MAKES IT MORE CONCRETE AND SUSTAINABLE.

WAYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION, "HOW TO USE THE MODEL".

At this point the STAGE II circle looks like this:

Stage II is now complete and the diagram of the process now looks like this:

STAGE I



STAGE II

NOTES BY USER OF THE PROCESS

STAGE III - ACTION

Stage IIIa - Asking what can be done

Many people reach the stage of committing themselves to a new behaviour but the decision is kept in a very vague, idealistic, or theoretical form. There is a need for a more concete approach. In Stage IIIa people are helped to express in concrete terms what it is they actually intend to do. They need constantly to be challenged to be sure that what they want to do is actually an ACTION.

The following questions help keep this stage concrete and action- oriented:

WHAT ACTUALLY WILL YOU DO:

QUESTIONS FOR STAGE IIIa

GENERAL QUESTIONS

How will you tell your:
- partner(s)
- children
- friends
- about your choices?

How are you going to put this change into practice?
How will you sustain it?

What will be the concrete signs of your change?

Who will be affected by your change?

How will you respond to any criticism, ridicule?

When will you start?

Who will help you start?

How can you tell your close friends about your plan?

What relationships will you have to change?

How do you plan to avoid or respond to pressure?

What will replace the unhealthy behaviours you are giving up?

QUESTIONS WHICH LEAD TO A GROUP STRATEGY

What can you do as a group to challenge, support, and sustain the proposed change of behaviour?

As a group, how can you cope or overcome the difficulties?

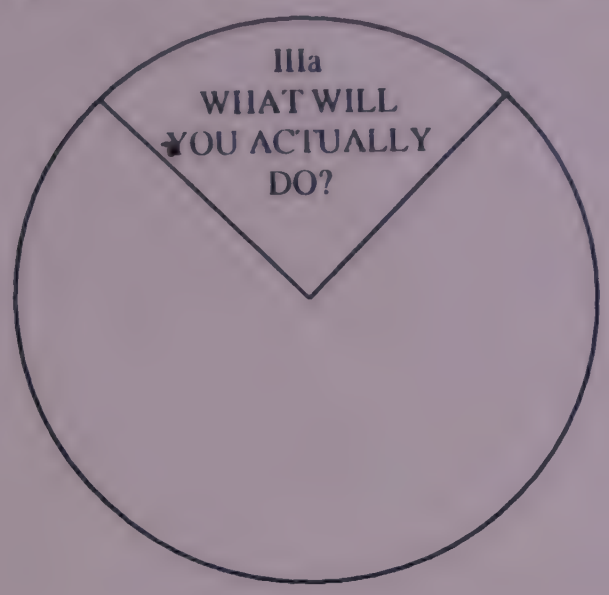
How can you make your group one of the popular ones?

How as a group can you earn extra money and support your members?

As a group, how can you have fun/ leisure together?

YS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION, "HOW TO USE THE DEL".

At this point the STAGE III circle looks like this:



NOTES BY USER OF PROCESS

Stage IIIb - Planning

It is not enough to know what one wants to do; people need to know how to do it. This Stage, IIIb, helps people to become aware of resources and approaches available to them. It is at this time that they devise practical steps which they will use to bring about the action they have chosen.

The following questions guide the person and the group in passing through this stage concretely and practically.

HOW WILL YOU DO IT?

QUESTIONS FOR STAGE IIIb

ALL QUESTIONS ARE GENERAL: PERSONAL

What makes your plan realistic and achievable?

Describe the practical steps you will take.

Where will you get the strength and courage to change?

Who will support and help you?

What meaning does your plan have in your life?

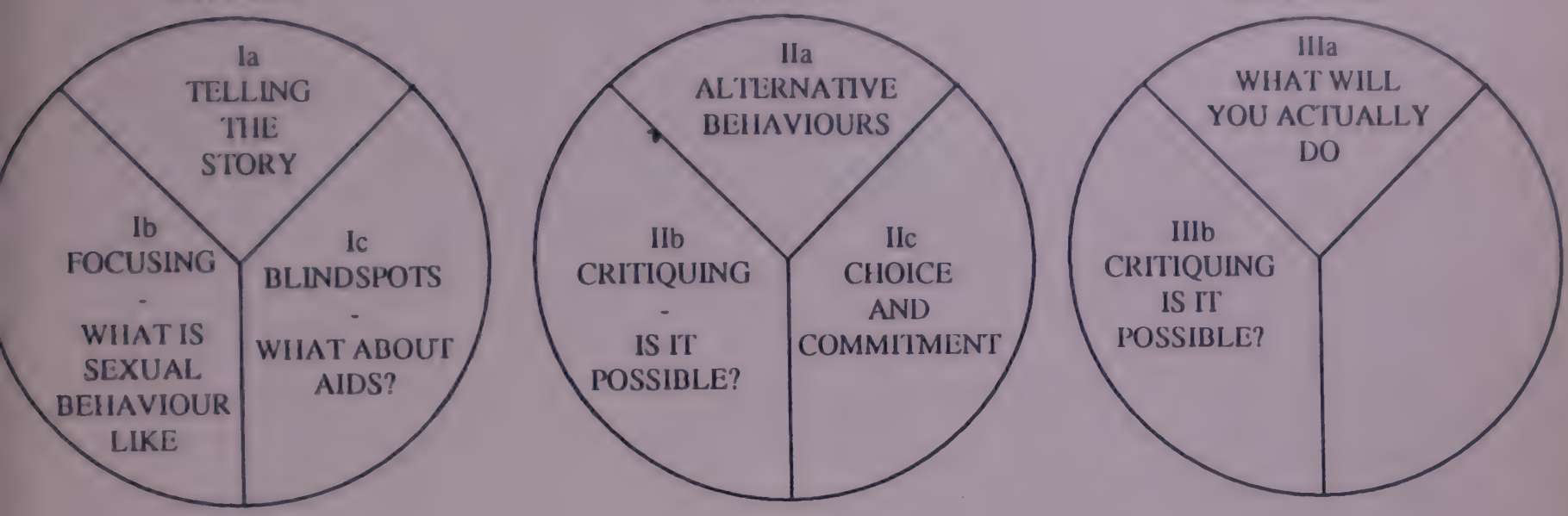
What problems may arise from the change you are making?

Who is the person you will turn to when you get stuck?

WAYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION, "HOW TO USE THE MODEL".

At this point the STAGE III circle looks like this:

THE PROCESS NOW LOOKS LIKE THIS:



<u>age IIIc - Doing it!</u>

nless one begins to act, all of the above remains simply an exercise. This stage, IIIc, sets one in motion. An important rt of this final section of Stage III is the consideration of what they will do when they get stuck.

ne following questions guide this important step of beginning to act:

OU DO IT!

QUESTIONS FOR STAGE IIIc

OR ALL GROUPS:

What will make this work?

What might get in the way?

What will you do if it starts to get too hard?

Who will try and make you fail?

To whom will you go for help?

What will you tell those who criticize you?

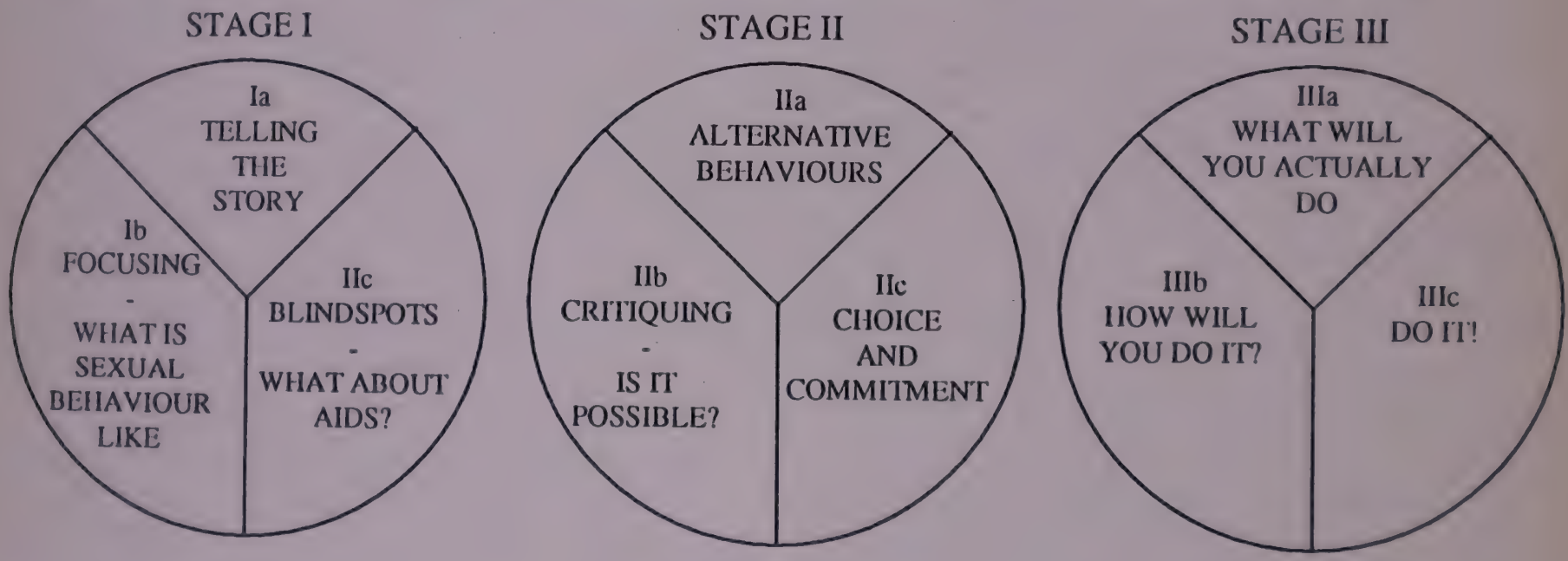
What part will prayer/God play in your action plan?

When are you going to start and how?

VAYS TO USE THESE QUESTIONS WILL BE DISCUSSED IN THE NEXT SECTION, "HOW TO USE THE MODEL".

At this point the STAGE III circle looks like this:

The diagram of the process is now almost complete: all stages have been filled in, It now looks like this:

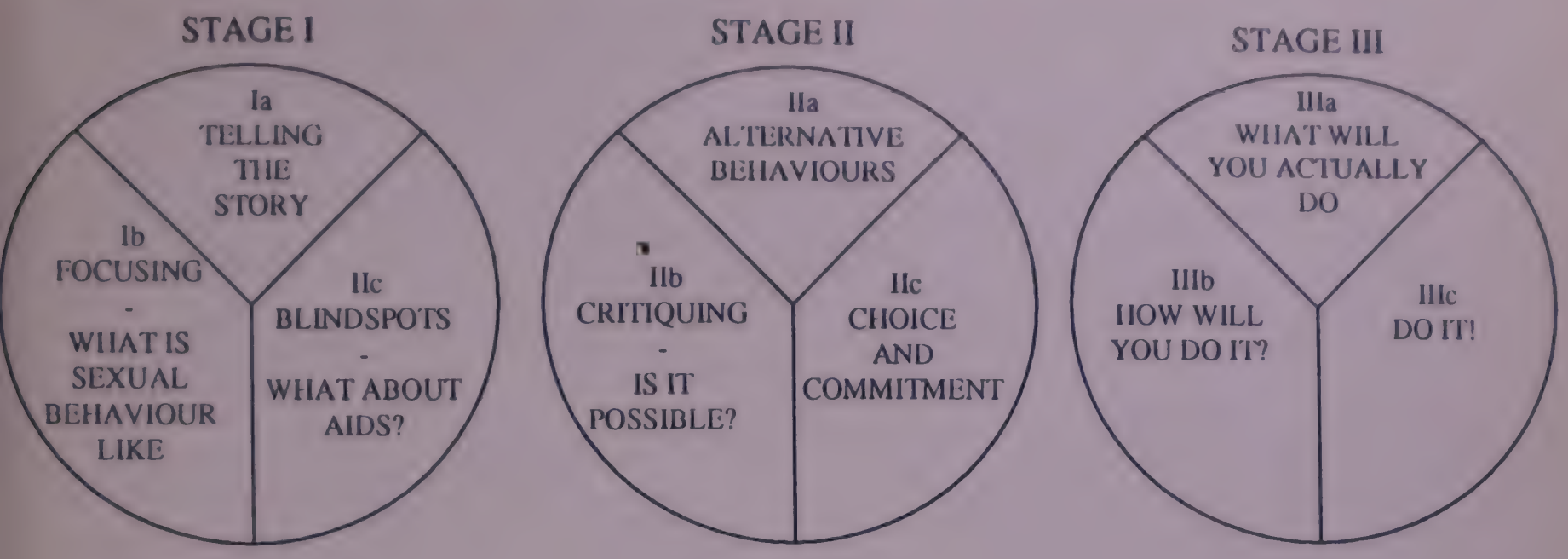


THROUGH ALL STAGES - ONGOING EVALUATION

It remains to add a final figure to the diagram; an "E" at the center of each Stage to remind one that evaluation is an essential part of the Process. Repeatedly in this booklet, it has been stated that, "...one never fails as long as one keeps trying". In other words, as long as one continues to work through the process one is in the process of changing. And that is LIFE. Actually, as soon as one begins to carry out the action chosen, that person's present reality has changed and the process begins again.

Evaluation means that one is aware at all times of where one is in the process. One may get stuck or need to go back and forth from one stage to another. This is normal; peoples' lives do not fit into a diagram. One simply needs to be aware that it is being done. Evaluation is the key that keeps the process moving and moving effectively.

is now possible to draw the diagram of the full "Education for Life" Process. It looks like this:



HOW TO USE THE MODEL

ASIC UNDERLYING PRINCIPLE

ver the years it has become clear that there is often confusion in the minds of those using this model. The confusion between the PROCESS and the various PROGRAMMES in which the process is used. The PROCESS is the nderlying stages which, when followed, help one to reach the goal of change. The PROGRAMME is the concrete ctivities used to enflesh these stages.

THE PROCESS REMAINS THE SAME - THE SAME 9 STAGES. THE WAYS IN WHICH THESE STAGES ARE ENFLESHED AND EXPERIENCED ARE UNLIMITED. IT IS IN UNDERSTANDING THE PROCESS THAT ONE IS ABLE TO DEVISE PROGRAMMES. THERE IS NO ONE RIGHT WAY TO USE "EDUCATION FOR LIFE".

he following section will attempt to make this clearer by outlining some of the factors that need to be considered in eciding how to make the best use of the process.

ACTORS THAT DETERMINE THE USE OF THE PROCESS
ND THE DESIGN OF A PROGRAMME

IME AVAILABLE

The process and its underlying philosophy can be used in any programme, regardless of the time available. It has been successfully used in programmes of a few hours, one day, a few days, and one week. It has also been used for short (one to two hours) sessions held on a weekly basis. EXPERIENCE HAS SHOWN THAT THE KEY IS TO MAKE THE BEST USE OF THE TIME AVAILABLE.

Short programmes need to be limited to fewer issues in order to reach the end of the process in the time available. THESE ISSUES SHOULD BE THE ONES MOST RELEVANT TO THE GROUP. The goal is always to get to ACTION.

The most effective seems to be a five-day programme. This allows for the building of trust and a greater degree of openness, the use of more creative exercises, and for a bonding that will provide ongoing support to the members of the group. THIS LONGER PERIOD IS FOR EXPERIENCING THE PROCESS AND DOES NOT INCLUDE TRAINING FOR FACILITATING THE PROCESS. More will be said about this in the section on Training and Preparation.

NUMBER OF PARTICIPANTS

The process itself can be used in a helping relationship with a single individual; it is an adaptation of Egan's counselling model. However, the "Education for Life" Model has been designed for use with groups. There is no rigid number. A very small group lacks enthusiasm and limits the activities that can be done; too large a group results in loss of control and poor participation. This last statement needs to qualified however; a large group can be considered as a gathering of many smaller groups, provided there are sufficient facilitators and sufficient space for activities. More experienced facilitators can usually manage larger groups.

AGE

The process can be used with groups of people of all ages. It is essential that the programme being designed takes into account both the age and' the developmental level of the participants. Each programme needs to be tailor made for the group; again, it is important to state that there is no one right way to use the process. Different age groups require different levels of information and sensitivity, especially with regard to sexuality and AIDS. This is especially true with adolescents and young adults; ten to fourteen (10 - 14) year old have usually not had the same degree of exposure of fifteen to twenty (15-20) year old.

CULTURAL AWARENESS

When preparing a programme for groups composed of people of different cultures or of people whose culture differs from that of the facilitators, it is essential that cultural implications be kept in mind. This is especially true in relationship to values and traditions related to sexuality.

RELIGION

Experience has shown that the effective use of the process resulting in sustainable change most often occurs with the inclusion of the spiritual dimension in the programmes. IT IS IMPORTANT THAT THE FAITH VALUES AND RELIGIOUS AFFILIATIONS BE RESPECTED AND CALLED FORTH FROM THE PARTICIPANTS.

GENDER

The experiences and views of life of men and women differ; each is very rich and needs to be valued. It is important in these programmes to allow participants to examine their reality in groups that allow free expression of all members. Many people using the process with mixed groups have found it helpful to have men and women discuss the issues separately at first; they then come together to share the insights gained. The ability to discuss sensitive subjects in mixed gender groups will vary with age, culture, and location.

AVAILABILITY OF ONGOING INDIVIDUAL HELP

There is a need for the facilitators to be alert to the fact that sensitive issues are being looked at. Some of these,

especially sexuality, fidelity, and HIV infection may result in stress for participants. The facilitator needs to watch for signs of psychological reactions and know how to assist the person or where to refer the person for help.

WHAT MAKES UP A PROGRAMME?

ne successful programme is made up of a combination of many varied activities and approaches. They are all ways making the process concrete. Those that have been found effective are:

input sessions
large group dialogue
sketches/drama
songs/music
videos
small group discussions
role plays
art work
testimonies
recreation/exercise
availability of one to one counselling
prayer/Word of God/meditation/Liturgy

ow these are put together in a programme depends on all the factors mentioned in the previous section.

ome concrete examples of each of these approaches will now be given. THIS SHOULD IN NO WAY LIMIT YOUR REATIVITY, BUT RATHER STIMULATE YOU TO BE CREATIVE.

INPUT SESSIONS

These are given AS THE ISSUES ARISE, staying with the FLOW OF THE PROCESS. Facilitators need to be well informed about the issues that commonly come up. These are especially in the areas of HIV/AIDS facts, sexuality, behaviour, addiction, and values.

HIV/AIDS facts: global and local picture, transmission, difference between HIV and AIDS, progression of the disease process, positive living. It is essential that the facilitator give accurate, up to date information and not his/her own opinions.

Behaviour: (see notes in this booklet for content). It is most important that this session be handled in a free and open manner. At no time should the approach be moralistic or preaching; the object is to assist the participants clarify their own positions.

Sexuality: this session must be given with ease and confidence. If the facilitator is not comfortable talking about the subject, it is better to get someone else to do it. An ill-at-ease presenter can give the group the impression that this is a "taboo" subject. Aspects to be covered include:

meaning and gift of human sexuality
relationships and intimacy
affection, touch, genital relations
homosexuality
abstinence/safer sex/condoms

Many facilitators find some of these issues hard to discuss. It is important that they realize that they are giving information and not their own opinions or choices. Their task is to help the participants make informed decisions about their own behaviour.

Addiction: this is related to a lack of intimacy and an attempt to fill the emptiness or dull the pain in one's life. Mention is made of the addictive cycle and the role addictions have in the transmission of HIV.

Values: participants need help to understand that a value is real when it is evident in their behaviour. The session helps them to clarify and prioritize their values.

This does not exhaust the topics with which the facilitators need to be familiar. If issues continue to surface while doing the process, material on those issues needs to be included.

INPUT SESSIONS SHOULD BE PRACTICAL, RELATED TO THE ISSUES ARISING IN THE GROUP, NON-JUDGEMENTAL, AND ACCURATE.

2. GROUP WORK:

Whether using full plenary sessions, large group dialogue, or small groups, the aim is to have the issues come from the group and not from the facilitator. The guideline questions provided for each stage of the process form the basis of these discussions.

3. SKETCHES/DRAMA

These are prepared in advance and performed by facilitators. Their purpose is to bring out a message in line with a stage in the process. They form the basis of discussions. Examples are "Life", "Secondary Virginity", and "True Love" in Appendix . These three are given in more detail to help you get started.

4. ROLE PLAYS

These are small dramas which the participants themselves create and act out; the subject matter comes from the questions in the various stages. These are very useful in a group to bring out the true reality and feelings which often do not get expressed in words.

5. ART WORK/SONGS AND MUSIC

There are various possibilities for the use of art media and music. Examples are:

- drawing pictures by participants
- collage work
- clay modelling
- interpretation of pre-selected pictures
- singing of songs (for giving messages and for animation)
- composing of songs

As with the other activities, the various stages of the process with their guide questions form the basis of these activities.

6. VIDEOS

These are tools highlighting specific issues which arise during the process. Some that have been found helpful are:

It's Not Easy
Born in Africa
No Second Chance
Cross and Switchblade
Making Choices
More Time

Faces of AIDS
The Way of The Cross
Lydia Wangesha - Facing The Challenge

7. TESTIMONY

All people are affected by the sharing of another's struggle/story. This can be used as a witness that change is possible and for encouragement. It is particularly useful in a peer situation.

8. PRAYER/WORD OF GOD/MEDITATION/LITURGY

These concretize the faith dimension of behaviour change. As such they are incorporated THROUGHOUT THE PROGRAMME. The religious affiliation of the participants is respected at all times and is actively incorporated into the programme, (for example, the Koran).

9. RECREATION/EXERCISE

It is important to be sensitive to the whole person and to provide times of recreation and exercise as the need arises. The subject matter of the discussions and activities is sensitive and often stressful; the facilitator needs to be aware of this and take breaks when needed.

10. AVAILABILITY OF COUNSELLING HELP

Because sensitive and sometimes frightening issues often arise during the activities (especially in relation to sexual behaviour and level of risk of HIV infection), the facilitators need to make it known that they are available for individual sessions. They also need to be ready to approach those who show signs of stress. Some issues that have seen to arise are homosexuality, rape, sexual abuse, and prostitution.

SUMMARY

"Education for Life" is a process that has been in use in Uganda for a number of years as part of some AIDS prevention programmes It is nothing magical or fool-proof; it provides an underlying philosophy and method for dealing with behaviour change.

There is no one "right" way to use the process. It can be enfleshed in many different programmes depending on the group being addressed and the creativity of the facilitators.

The inclusion of a spiritual component in a programme has been shown to increase the sustainability of the behaviour change. It is essential that this spiritual component respect the religious beliefs and affiliations of the participants.

The best preparation for using "Education for Life" is to go through the process oneself. After that, further training may be necessary depending on the background and experience of the future facilitator.

BEHAVIOUR CHANGE IS POSSIBLE.

This does not mean that it is easy. It is an ongoing process and is best sustained when supported by a group with regular follow-up activities.